

**Relationships between cognitive status,
speech impairment and communicative participation in Parkinson's disease**

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Abstract

Aim: To assess the relationships between cognitive status, speech impairment and communicative participation in Parkinson's disease.

Introduction: Speech and communication difficulties, as well as cognitive impairment, are prevalent in Parkinson's. The contributions of cognitive impairment and acoustic speech characteristics remain equivocal. Relationships between Impairment and Participation levels of the International Classification of Functioning, Disability and Health (ICF) have not been thoroughly investigated.

Methods: 45 people with Parkinson's and 29 familiar controls performed read, mood and conversational speech tasks as part of a multimethod investigation. Data analysis formed three main parts. Depression, cognition and communication were assessed using questionnaires. Phonetic analysis was used to produce an acoustic characterisation of speech. Listener assessment was used to assess conveyance of emotion and intelligibility. Qualitative Content Analysis was used to provide a participant's insight into speech and communicative difficulties associated with Parkinson's disease.

Results: Cognitive status was significantly associated with certain read speech acoustic characteristics, emotional conveyance and communicative participation. No association was found with intelligibility or conversational speech acoustic characteristics. The only acoustic speech characteristics that predicted intelligibility were intensity and pause in the read speech condition. The contribution of intelligibility to communicative participation was modest. People with Parkinson's disease reported a range of psychosocial, cognitive and physical factors affecting their speech and communication.

Conclusions: I provide evidence for a role for cognitive status in emotional conveyance and communicative participation, but not necessarily general speech production, in Parkinson's disease. I demonstrate that there may not be a strong relationship between ICF Impairment level speech measures and functional measures of communication. I also highlight the distinction between measures of communication at the ICF Activity and Participation levels. This study demonstrates that reduced participation in everyday communication in Parkinson's disease appears to result from a complex interplay of physical, cognitive and psychosocial factors. Further research is required to apply these findings to contribute to future advances in speech and language therapy for Parkinson's disease.

Statement of length

This thesis contains 73,940 words.

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List of abbreviations

Abbreviation	Explanation
A-Level	Advanced Level
AS-Level	Advanced Subsidiary Level
AMA	American Medical Association
BA	Bachelor of Arts
BEd	Bachelor of Education
BEng	Bachelor of Engineering
BSc	Bachelor of Science
BTEC	Business and Technology Education Council
CamPaIGN	Cambridgeshire Parkinson's Incidence from GP to Neurologist
CES	Communicative Effectiveness Survey
CP	Conversation partner
CPIB	Communicative Participation Item Bank
CRTU	Clinical Research and Trials Unit
DSM	Diagnostical and Statistical Manual of Mental Disorders
F_0	Fundamental frequency
F_0SD	Standard deviation of fundamental frequency
FCR	Formant Centralization Ratio
GCSE	General Certificate of Secondary Education
GP	General Practitioner
HADS	Hospital Anxiety and Depression Scale
HNR	Harmonic-to-noise ratio
ICF	International Classification of Functioning, Disability and Health
ICICLE-PD	Incidence of Cognitive Impairments in Cohorts with Longitudinal Evaluation- Parkinson's Disease
IQR	Inter-quartile range
LEDD	Levodopa equivalent daily dose
MA	Master of Arts
MDS	Movement Disorder Society
MEd	Master of Education
MEng	Master of Engineering
MoCA	Montreal Cognitive Assessment
MMSE	Mini-Mental State Examination
MNF_0	Mean fundamental frequency
ms	Milliseconds

MSc	Master of Science
NHS	National Health Service
NNUH	Norfolk and Norwich University Hospital
NRES	National Research Ethics Service
O-Level	Ordinary Level
PD	Parkinson's disease
PGCE	Postgraduate Certificate of Education
PhD	Doctor of Philosophy degree (doctorate)
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
PwPD	Person (people) with Parkinson's disease
R&D	Research and Development
/s/ ASD	Standard deviation of the amplitude of /s/
SD	Standard deviation
UEA	University of East Anglia
UK	United Kingdom
UPDRS	Unified Parkinson's Disease Rating Scale
VOTr	Voice onset time ratio
VSA	Vowel Space Area
WHO	World Health Organization

Chapter 1: Preface

1.1 Overview of thesis

This thesis presents the results of a cross-sectional observational study with embedded within-participants and qualitative elements. It investigates the impact of cognitive impairment on speech and everyday communication in Parkinson's disease (PD), in addition to assessing the inter-relationships between measures of speech impairment and communicative participation. Chapter one summarises why I conducted this study, why I was suitable for this role and how my thesis makes an original contribution to knowledge. Chapter two provides an introduction to PD, progressing to discuss its impact on cognition, speech and communication. Chapter three presents the results of my systematic review assessing the state of extant knowledge about the relationships between cognitive status, and speech and communication impairments in PD. Chapter four provides an account of the aims, methodology and principal methods in my study. Chapter five presents specific methods and results of the speech analyses, while chapter six presents the communicative analyses. Chapter seven discusses the results of my study in the context of the extant body of literature, evaluates its relative strengths and limitations, and asserts its contribution to knowledge and doctoral worthiness.

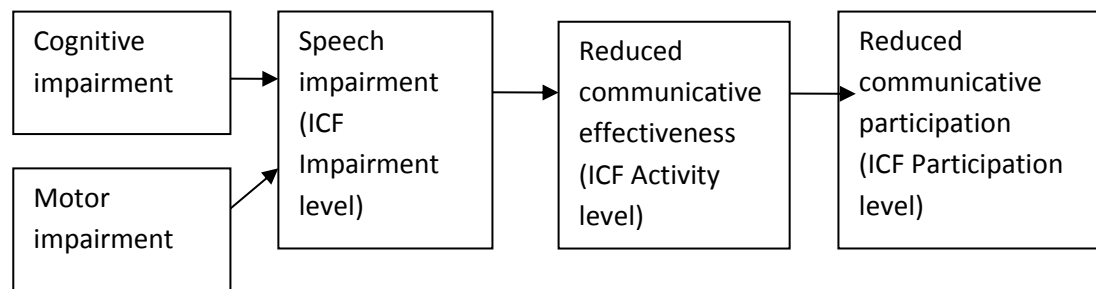
1.2 Summary rationale

PD is the second most prevalent neurological disability in the United Kingdom (UK). As an age-related neurodegenerative condition, it is associated with increased retirement and institutionalisation, which are both costly for society. PD frequently impacts upon cognitive status, speech and communication. However, few studies have investigated relationships between these aspects. An area that has received particularly limited attention is the relationship between cognitive status and participation in everyday communicative activities, which I shall call communicative participation following Eadie et al (2006) and Baylor et al (2009). Whereas there is evidence that participation is important for people with Parkinson's disease, the majority of research has focused on the Impairment level of the International Classification of Functioning, Disability and Health (ICF) (World Health Organization, 2001). This research has not clearly established which acoustic characteristics of speech contribute most to reduced intelligibility and emotional conveyance in PD. Therefore, in this thesis I seek to provide an overview from motor and cognitive impairment, through speech impairment to reduced communicative participation in PD.

1.3 Statement of original contribution to knowledge

My thesis provides a thorough overview of the pathway from cognitive impairment through speech impairment to reduced communicative participation in PD. The figure below depicts this pathway in the context of the ICF.

Figure 1: Pathway to reduced communicative participation in Parkinson's disease



In particular, for the first time, my thesis investigates the relationship between cognitive status and communicative participation in PD, using both a cognitive assessment known to be sensitive to mild cognitive impairment in PD and a communicative assessment that focuses on the Participation rather than the Activity level of the ICF. Moreover, it provides a detailed assessment of the relationships between speech acoustics, intelligibility and emotional conveyance. In addition to its international relevance, this study is, to my knowledge, the first study of the acoustic speech characteristics of people with PD to be conducted using a British accent of English.

1.4 Researcher credentials

My background is in modern and medieval languages originally. While studying this subject at the University of Cambridge, I developed a particular interest in language structure and use in society, which led me to complete my degree in linguistics. While studying linguistics at Cambridge, I took a module in experimental psychology, which led to an interest in the psychology of language. Therefore, I enrolled on a Master of Science (MSc) course at University College London to study Speech and Hearing Sciences. This provided an in-depth coverage of areas as diverse as speech perception, audiology and developmental linguistics, including the latest research. I also completed a module in research design and statistics. This degree showed me for the first time the potential clinical relevance of speech and language research.

Therefore, following two years out of academia, during which I applied my language skills to teaching English as a foreign language, I decided to look for a Doctor of Philosophy degree (PhD) in a subject that combined my speech and language expertise with real-world applicability. Therefore, I successfully applied for this opportunity to study for my PhD at the University of East Anglia with supervisors Drs Deane, Horton and Butterfint on this project investigating the impact of cognitive status on speech impairment and communicative participation in Parkinson's disease. Dr Deane is a systematic reviewer and research methodologist, Dr Horton an academic speech and language therapist and Dr Butterfint a phonetician.

From my previous degrees, I have experience in both quantitative and qualitative methods. I also have prior experience in conducting phonetic analysis and listener studies. Therefore, I was ideally suited to this study that employed a wide range of methods. Additionally during my time at the University of East Anglia, I completed an extensive training programme, consisting of internally organized courses as well as courses from external providers, including the National Research Ethics Service (NRES), the National Health Service (NHS) and the Society for Research into Higher Education, of which I am a student member. These courses have increased my knowledge and skills in areas as diverse as ethics, research methods, dissemination and commercial awareness. I also maintain an eclectic range of research interests, including social and cognitive psychology, philosophy, education and literature. Therefore, I believe I was a suitable researcher to conduct this multifaceted study.

1.5 Stylistics

In writing this thesis, I had to make some writing style decisions, which are mainly a matter of personal stylistic preference. Therefore, before concluding this preface, I wish to state the stylistic judgements I have made and provide rationale for these decisions.

There is disagreement regarding the most suitable narrative person and voice to write a work of this nature. Regarding person, there is a choice between the first person singular and the first person plural. The first person plural is often used by media commentators and columnists in a construction popularly called the 'editorial we'. Some authors use the first person plural to engage and include the reader. This is referred to as the 'author's we' or by the Latinate form 'pluralis modestiae' (plural of modesty). In counterpart, the majestic plural form can be used to refer to a single person holding a high office. In linguistics, the use of the plural pronoun to refer to one person using the constructions described above is called *nosism*. *Nosism* can be seen as majestic or modest depending on the context. Regarding voice, there is a choice between active and

passive voice. In the latter, the agent (the person who performs the action) can be expressed or suppressed.

I decided to use the first person singular as my default narrative person and an active voice. This means that I used sentences such as 'I made this decision' (first person singular active) rather than 'we made this decision' (first person plural active) or 'this decision was made' (passive voice with agent suppressed). Nosism in a doctoral thesis is criticised by some academics, who believe that this style does not demonstrate sufficient personal responsibility for the work on the part of the candidate. I agree that 'we' is not the optimal narrative person for a thesis.

Regarding voice, there are academics who prefer passive voice, suggesting that a first person active style reads excessively like a diary. There are others who prefer the first person active style, suggesting that the passive voice does not portray sufficient personal responsibility for the work. I have decided to write the thesis using first person active as the default writing style. When a decision was taken jointly by members of the study management group that I chaired, I used the passive voice with the agent suppressed. This form emphasises the process rather the agent.

In describing PD and its symptoms, I reserved the use of capitals for established syndromes and disorders. I did not capitalise abstract concepts such as quality of life or communicative participation, or putative syndromes such as mild cognitive impairment. In discussing phonetic analyses, capitals were used for names of specific measures or formulae such as Formant Centralization Ratio, but not more generic concepts such as voice onset time or jitter.

Chapter 2: Introduction to Parkinson's disease and its effect on cognition, speech and communication

2.1 Signposting

This chapter starts by introducing the reader to the key features of PD. Then it addresses how PD impacts on cognition. Finally, it explores the speech and communicative impairments associated with PD.

2.2 Introduction to Parkinson's disease

2.2.1 Epidemiology

PD is a common neurodegenerative condition affecting around 1.5% of people over 65 (von Campenhausen et al., 2005). It has been shown to impinge significantly upon quality of life (Schrag et al., 2000, Kuopio et al., 2000) and is associated with increased early retirement (Hely et al., 2005, Hely et al., 1999, Hely et al., 2008, Martikainen et al., 2006) and mortality (Hely et al., 2005, Hely et al., 1999, Hely et al., 2008, Hughes et al., 2004). The world's population is experiencing an unprecedented, pervasive, profound and enduring ageing process (United Nations, undated, Lutz et al., 2008). Therefore, age-associated conditions such as PD pose a major healthcare challenge of the future.

2.2.2 Symptom overview

PD is most commonly associated with its motor symptoms, upon which diagnostic criteria such as the UK Parkinson's Disease Society Brain Bank criteria (Daniel and Lees, 1993, Gibb and Lees, 1988) are based. The key motor signs of PD are tremor, rigidity, bradykinesia (slowness of movement) and postural instability. However, PD has been associated with a wide range of non-motor symptoms, including autonomic dysfunction, cognitive and psychiatric disturbances (Chaudhuri et al., 2006, Shulman et al., 2002, Poewe, 2008, Chaudhuri et al., 2005). There is evidence that non-motor symptoms may have a greater impact on quality of life than motor symptoms (Martinez-Martin et al., 2011, Soh et al., 2011). Impairment of activities of daily living has been shown to be more important for quality of life than mobility limitations per se (Holroyd et al., 2005, Soh et al., 2013). These findings emphasise the importance of the activity and participation levels of the ICF, as opposed to purely the impairment level. In this thesis, I will sometimes use the term impairment to refer specifically to the ICF Impairment level, in contrast with the

Activity and Participation levels. However, at other times I will use the term more broadly, as will be evident from the context, to refer to all speech and communication difficulties.

2.2.3 Pathophysiology

The precise pathogenic mechanisms of PD remain unclear (Jenner, 2013), although they are believed to relate to α -synuclein dysfunction (Recchia et al., 2004, Goris et al., 2007). Traditionally, PD was conceptualised as purely a dopaminergic disorder resulting from the death of dopaminergic cells in the striatum in the midbrain (Damier et al., 1999, Soukup and Adams, 1986). However, more recently PD has been shown to be a wide and diverse multi-pathology, implicating cholinergic, serotonergic and noradrenergic systems (Braak et al., 2003, Ballanger, 2013, Jenner, 2013).

Three main dopaminergic pathways have been shown to be implicated in PD. Impairment of the nigrostriatal pathway, which connects the substantia nigra and the striatum within the midbrain and forms part of the basal ganglia motor loop, contributes to the movement impairments characteristic of PD (Riederer and Wuketich, 1976, Leenders et al., 1990). Impairment of the mesocortical pathway (Javoy-Agid and Agid, 1980), which connects the ventral tegmentum in the midbrain to the frontal cortex, contributes to cognitive impairment in PD (Lewis et al., 2003). Impairment of the mesolimbic pathway (Schott et al., 2007), which connects the ventral tegmentum to the prefrontal cortex via the limbic system, contributes to cognitive impairment (Lewis et al., 2003) and impaired emotional processing (Schott et al., 2007, Fitzgerald et al., 2006) in PD. Mood disturbances in PD have been demonstrated to be an intrinsic component of the condition with impairment of the mesocortical and mesolimbic pathways posited as a mechanism of action (Lieberman, 2006). The relative contribution of intrinsic neurochemical and psychological response factors to depression in PD remains unclear. Self-perception of severity of disability has been shown to be a significant predictor of depression in PD (Schrag et al., 2001).

Beyond the dopamine system, the cholinergic (Bohnen et al., 2006, Klein et al., 2010), serotonergic (Hawkes et al., 2010, Calabresi et al., 2006) and noradrenergic (Calabresi et al., 2006, Vazey and Aston-Jones, 2012) systems have also been implicated in PD cognitive impairment. Comparatively little is known with regard to the exact pathophysiological underpinnings or behavioural mechanism of action of speech and communicative impairments associated with PD. My study explores the hitherto unconfirmed relative contributions of motoric, cognitive and psychosocial factors to everyday communication difficulties in PD. As discussed above, psychosocial factors could result from a combination of intrinsic neurochemical changes associated with PD

and a psychological response to other disabling symptoms of PD. Motor speech impairments appear to result from a combination of anatomical and physiological alterations to the speech musculature and impaired transmission of motor signals from the brain to the speech organs (Rahn et al., 2007, Hirose, 1986, Ho et al., 1999a).

2.3 Cognitive impairment in Parkinson's disease

2.3.1 Overview

The following sections provide an overview of cognitive impairment in PD. They discuss suggested criteria for mild cognitive impairment, prevalence, phenotypes and the pathway to dementia.

2.3.1.1 Criteria

A variety of criteria for mild cognitive impairment has been proposed. Some of these criteria have not been developed specifically for PD. Petersen et al (1999) proposed that a diagnosis of mild cognitive impairment requires each of the following: memory complaint, normal activities of daily living, normal general cognitive function, abnormal memory for age and absence of dementia. The National Institute on Aging-Alzheimer's Association workgroups on diagnostic guidelines for Alzheimer's disease published criteria for mild cognitive impairment (Albert et al., 2011). These guidelines stated that there should be concern about a deterioration in cognitive function, evidence of impairment in at least one cognitive domain relative to age- and education-adjusted norms, preservation of functional independence, with only mild difficulty performing complex tasks and no evidence of dementia or significant impairment of social and occupational functioning.

The recently published *Diagnostic and Statistical Manual of Mental Disorders 5th edition (DSM-5)* (American Psychiatric Association, 2013) introduced a concept called 'minor neurocognitive disorder'. The DSM-5 uses a six domain cognitive profile: complex attention, executive function, learning and memory, language, perceptual-motor function and social cognition. For a diagnosis of minor neurocognitive disorder, four criteria must be satisfied. Firstly, there must be evidence of cognitive decline in at least one domain, preferably using standardised neuropsychological tests. Secondly, the cognitive deficits must not interfere with capacity for independent living, although greater effort and the use of compensatory strategies may be required. Thirdly, the cognitive deficits must not occur exclusively in the context of delirium. Fourthly, the deficits must not be explained more readily by another condition.

Specifically in the context of PD, Aarsland et al (2009) created a set of mild cognitive impairment criteria for use in the Norwegian Park West study (see section 2.3.1.4). These criteria used a three-domain cognitive profiling system: attention and executive function, memory, and visuospatial function. Composite standardised Z scores were calculated for each of the three domains. Mild cognitive impairment was defined as at least 1.5 standard deviations below the adjusted norm for at least one of the three domains.

In an attempt to unify the conceptualisation of mild cognitive impairment in PD and improve comparability across studies, a Movement Disorder Society (MDS) task force (Litvan et al., 2012) has recently published new criteria. These criteria offer two levels of assessment. The first level assesses for possible mild cognitive impairment, using an abbreviated global cognitive assessment or a limited neuropsychological battery, with only one test per cognitive domain (see section 2.3.1.3) or which does not assess each of these five domains. Impairment must be found either on the abbreviated cognitive assessment or on at least two tests of the limited battery, using recommended cut-offs for these assessments. The second level assesses for mild cognitive impairment, using a comprehensive neuropsychological battery and can provide subtyping information (see section 2.3.1.3). This assessment requires at least two tests for each of the five cognitive domains. For a level two diagnosis of mild cognitive impairment using MDS criteria, impairment must be found on at least two tests. This can be manifested by performance between one and two standard deviations below adjusted norms, significant decline on repeated testing or significant decline from estimated premorbid levels. The task force now aims to validate these criteria (Geurtsen et al., 2013). However, as can be seen above, the vision of a single set of unified criteria for mild cognitive impairment in PD remains distant.

The DSM-5 (American Psychiatric Association, 2013) criteria for major neurocognitive disorder, which was called dementia in previous editions, also contain four elements. Firstly, there must be evidence of significant cognitive decline from previous functioning on at least one DSM-5 cognitive domain, preferably using standardised neuropsychological testing. Secondly, cognitive deficits must interfere with independent living. Thirdly, cognitive deficits must not occur exclusively in the context of delirium. Fourthly, the deficits must not be more readily explained by another condition.

2.3.1.2 Prevalence

As a result of the variable criteria applied for mild cognitive impairment, comparing point prevalence figures across studies is problematic. Studies also vary in terms of

whether prevalent or incident PD is sampled. Recent work has shown that prevalence estimates can vary widely depending on the instruments and cut-offs used (Marras et al., 2013, Yarnell et al., 2013). For example, the baseline cognitive data (Yarnell et al., 2013) from the Incidence of Cognitive Impairments in Cohorts with Longitudinal Evaluation-Parkinson's Disease (ICICLE-PD) study into incident PD showed that prevalence rates for mild cognitive impairment, using MDS level two criteria (Litvan et al., 2012) were 65.8% at 1, 42.5% at 1.5 and 22.5% at 2 standard deviations below adjusted norms. Further standardisation of criteria and cut-offs is required to provide more comparable data on the prevalence of mild cognitive impairment in PD. An MDS systematic review (Litvan et al., 2011) showed a mean prevalence of mild cognitive impairment in PD of 26.7% (range 18.9%-38.2%) across eight studies. However, this result should be interpreted cautiously due to considerable heterogeneity across studies and the publication of new criteria subsequent to this review.

2.3.1.3 Phenotypes

The MDS criteria (Litvan et al., 2012) propose five key domains of cognitive impairment: attention and working memory, executive function, language, memory and visuospatial function. Executive function is an umbrella term for cognitive processes that regulate or manage other cognitive processes (Elliott, 2003), acting like the brain's chief executive. It is debatable whether executive function can be clearly dissociated from the cognitive functions that it serves, for example attention and working memory. Studies have consistently found that non-amnesic single domain mild cognitive impairment is the most common phenotype in PD (Aarsland et al., 2009, Yarnell et al., 2013, Aarsland et al., 2010, Janvin et al., 2006).

2.3.1.4 Natural history

PD is associated with a prodrome of at least five years (Fearnley and Lees, 1991). Although cognitive impairment can be found at baseline in incident PD cohorts, no cognitive precursors of PD have yet been established. PD has been associated with significantly increased rate of cognitive decline compared to normal ageing (Hely et al., 2005, Muslimović et al., 2009, Stepkina et al., 2010). Mild cognitive impairment rates at baseline using incident cohorts have included 36% in the Cambridgeshire Parkinson's Incidence from GP to Neurologist (CamPaIGN) study (Foltynie et al., 2004) and 19% in the Norwegian ParkWest study (Aarsland et al., 2009). The ICICLE-PD study aims to validate the results of the CamPaIGN study and provide greater detail of cognitive profiling. Baseline data (Yarnell et al., 2013) show that 42% of people with PD met the

level one MDS criteria (Litvan et al., 2012) for possible mild cognitive impairment and that using level two criteria, the prevalence of mild cognitive impairment in people with PD was 66% at one standard deviation below adjusted norms, 43% at 1.5 standard deviations below adjusted norms and 22% at two standard deviations below adjusted norms.

Pedersen et al (2013) showed that participants with mild cognitive impairment at baseline were over 27 times more likely to develop dementia by three years than those with intact cognitive status at baseline. Ten per cent of participants in the CamPaIGN study had developed dementia by three to five years (Williams-Gray et al., 2007), with a mean time to dementia of six and a half years (Evans et al., 2011). The Sydney multicentre study, which is to date the only incident natural history study of PD to reach 20 years, had dementia prevalence rates of 48% at 15 years and 83% at 20 years (Hely et al., 2005, Hely et al., 2008).

Studies disagree with respect to which aspects of cognitive function are most predictive of progression to dementia. Using a prevalent cohort, Janvin et al (2006) found that single domain non-amnesic mild cognitive impairment and multiple domain mild cognitive impairment were significant risk factors for dementia, whereas single domain amnesic mild cognitive impairment was not. Levy et al (2002) found, using a prevalent cohort, that memory and executive function were the key predictors of dementia. In the Norwegian ParkWest study, Pedersen et al (2013) found that attention and verbal memory predicted progression to dementia. However, the CamPaIGN study (Williams-Gray et al., 2009) found that semantic fluency and pentagon copying, rather than executive function, were the strongest cognitive predictors of accelerated cognitive decline.

2.3.2 A more detailed account of aspects of cognitive impairment

The following paragraphs explore three aspects of cognitive impairment in Parkinson's disease in greater detail, presenting both seminal and recent work.

2.3.2.1 Memory and learning

Substantial variability in the memory and learning profiles of people with PD has been observed (El-Awar et al., 1987). Impaired memory recall has been widely attested (Muslimović et al., 2005, Green et al., 2002). The majority of studies (Appollonio et al., 1994, Harrington et al., 1990) have demonstrated a beneficial effect of recall aids. Many studies have shown a relationship between recall performance and executive function

(Higginson et al., 2003, Cooper et al., 1991). Impaired remote memory of events in the distant past has been shown (Leplow et al., 1997, Venneri et al., 1997). However, implicit memory has not been shown to be implicated (Appollonio et al., 1994).

Working memory has been shown to be impaired from the early stages of PD (Kensinger et al., 2003), with consequent effects on a range of cognitive functions, including recall (Higginson et al., 2003) and planning (Kliegel et al., 2005). The majority of studies support the executive theory of working memory (Gilbert et al., 2005, Lewis et al., 2003). Equivocal results have been found regarding the impact of PD on rule-based categorisation and procedural skill learning. Studies with greater reliance on feedback (Filoteo et al., 2005, Shohamy et al., 2004, Osman et al., 2008) and higher attentional load (Ashby et al., 2003) have shown the most significant impairments.

2.3.2.2 Attention

Impaired divided attention has frequently been found in PD and shown to relate to executive function deficits (Sharpe, 1996, Dalrymple-Alford et al., 1994). Selective attention deficits have been found by some studies (Maddox et al., 1996, Dujardin et al., 1999). Attention-shifting impairments have often been found using the simplified (Tomer et al., 2007, Owen et al., 1993) but not the original (Lewis et al., 2005) Wisconsin Card Sorting Test (Grant and Berg, 1948). The simplified test matches along only one dimension and it has been suggested that attested impairment on the simplified test relates to the additional attention demands introduced by the absence of reinforcement of irrelevant dimensions. Studies using the more sophisticated Intradimensional/Extradimensional Test have found the greatest and most consistent impairments at the extra-dimensional shift stage (Slabosz et al., 2006, Downes et al., 1989), which involves switching the dimension of interest rather than the value of the same dimension.

2.3.2.3 Planning and problem solving

Planning efficiency has been shown to be compromised in PD. People with Parkinson's disease (PwPD) solved fewer problems in the minimum number of moves (Muslimović et al., 2005) and formed less complex intentions than matched controls (Kliegel et al., 2005). However, there is little evidence for impaired planning success. No reduction in successful problem solving on easy and intermediate Tower of Hanoi (Lucas, 1893) problems or in intention fidelity has been shown (Schneider, 2007, Kliegel et al., 2005). Reduced problem solving success was found for difficult Tower of Hanoi problems (Schneider, 2007). However, this finding may be explained by an increased abandonment rate due to elevated fatigue levels in PwPD (Karlsen et al., 1999, Herlofson and Larsen,

2003) and inefficient planning strategy, which both increase the time required to complete the task.

2.3.3 Demographics

Increased age (Williams-Gray et al., 2007, Aarsland et al., 2010, Riedel et al., 2008) and age at onset (Aarsland et al., 2010, Riedel et al., 2008) have been shown to associate significantly with increased risk of cognitive impairment in PD. The contribution of gender remains equivocal. Aarsland et al (2010) found that men with PD had a significantly greater risk of mild cognitive impairment than women. However, it must be noted that while cognitive assessment was comprehensive, it was not standardised across research sites. On the other hand, Riedel et al (2008) found no significant gender differences using the Mini Mental State Examination (MMSE) (Folstein et al., 1975) or the Parkinson Neuropsychometric Dementia Assessment (PANDA) (Kalbe et al., 2008) and found greater cognitive impairment for women using a clock drawing task. The CAMpaIGN study (Williams-Gray et al., 2007) found no significant association between gender and risk of cognitive impairment. Significant positive associations between cognitive impairment, and disease severity (Aarsland et al., 2010, Riedel et al., 2008) and disease duration (Riedel et al., 2008) have been demonstrated.

2.3.4 Depression

Depression has been shown to associate with increased cognitive impairment in PD (Schrage et al., 2001, Holroyd et al., 2005, Diab et al., 2013). A review by Lieberman (2006) suggests that, as a result of shared neural circuitry, depression in PD may result in increased cognitive impairment. However, Schrage et al (2001) suggests that cognitive impairment in PD may contribute to depression. Some studies investigating samples with milder depression have found no significant association with cognitive status (Boller et al., 1998, Starkstein et al., 1989). The mechanisms of action and causal direction of the relationship between depression and cognitive impairment in PD remain unclear.

2.3.5 Medication

Studies investigating mild PD have shown either a beneficial or no effect of levodopa on cognition (Cooper et al., 1992, Kulisevsky et al., 2000, Growdon et al., 1998), whereas studies investigating moderate to severe PD have shown either a detrimental or no effect (Morrison et al., 2004, Lange et al., 1992, Girotti et al., 1986). The levodopa overdose theory (Gotham et al., 1988) claims that in early PD levodopa may improve

cognitive functions associated with the severely depleted dorsal striatum (Kish et al., 1988), while impairing functions associated with the less affected ventral striatum.

Task-specific effects have frequently been found. Beneficial effects on attention shifting (Cools et al., 2003), memory, digit ordering (Cooper et al., 1992), planning and spatial working memory (Lange et al., 1992, Owen et al., 1993) have been found in mild PD. Learning has been the aspect most frequently reported to be impaired by levodopa (Gotham et al., 1988, Shohamy et al., 2006). Similar tasks have sometimes produced apparently contradictory results. This may result from levodopa increasing overall dopamine levels in target areas (Yamato et al., 2001) rather than providing a substitute for the natural phasic dopamine response to stimuli (Horvitz, 2000, Schultz, 2002), which is an important aspect of feedback learning (Shohamy et al., 2004). No beneficial effects of anticholinergic medication on cognition have been demonstrated. Anticholinergic medication has been associated with impaired executive function (Cooper et al., 1992, Bédard et al., 1999). With regard to total medication load, Aarsland et al (2010) and Williams-Gray et al (2007) showed no significant association between levodopa equivalent daily dose and cognitive status.

2.4 Speech and communication in Parkinson's disease

Section 2.4.1 provides an overview of the impact of PD on speech and communication. Section 2.4.2 proceeds to explore this topic in greater detail.

2.4.1 Overview

In the context of this thesis, it is important to differentiate between speech and communication. I use the term speech to refer to the production and perception of sounds to convey meaning and emotion, and the term communication to mean the use of speech and language in everyday situations.

Between 74 and 89% of people with PD have impaired speech (Ho et al., 1999b, Logemann et al., 1978, Sapir et al., 2001, Müller et al., 2001). Speech impairment in PD is associated with lower quality of life and maladaptive coping strategies (Heberlein and Vieregge, 2005). As detailed in section 2.4.2, voice impairments are the most prevalent speech alterations and occur earliest, although impairments of pitch, loudness, articulation and rhythm can also be found. PD is associated with reduced intelligibility, although the contribution of acoustic factors has not yet been established (see section 2.4.2.5).

Around 70% of people with PD report significant dissatisfaction with their everyday communication (Miller et al., 2008b). The association between impaired everyday communication and quality of life is difficult to study. Communication is seen as so integral to quality of life that it is included in quality of life instruments such as PDQ-39 (Jenkinson et al., 1997). Miller et al (2011a, 2008b, 2006) reveal that a complex interaction of physical and psycho-social factors affects communication in PD.

2.4.2 A more detailed account

The following sections explore a number of aspects of speech and communicative impairment in greater detail, exploring both seminal and recent work. Speaker and listener perspectives are presented. Technical terms are explained in the glossary.

2.4.2.1 Voice and prosody

Voice impairments, which refer to problems with periodic vibration of the vocal folds, are believed to be the most prevalent speech difficulties in PD and are associated with the earliest onset (Logemann et al., 1978, Ho et al., 1999b). They have been cited as an important factor in social embarrassment and introversion (Miller et al., 2006). Acoustic, photoglottographic and perceptual studies have demonstrated voicing impairments in PD, including increased jitter, shimmer and speed quotient, as well as structural laryngeal abnormalities and reduced temporal control of voicing and fundamental frequency range (Gamboa et al., 1997, Fraïle and Cohen, 1999, Lin et al., 1999, Zwirner et al., 1991, Yüçetürk et al., 2002). Voice-related impairments contribute to prosodic impairments, such as impaired grammatical and emotional intonation and disproportionate reduction of unstressed syllables (Le Dorze et al., 1998, Ackermann and Ziegler, 1991, Möbes et al., 2008). However, the way humans perceive fundamental frequency as pitch is approximately logarithmic rather than linear (Zhang, 2013).

2.4.2.2 Loudness

Reduced loudness is a commonly attested consequence of PD. In addition to a reduction of overall intensity, people with PD have been shown to experience increased intensity decay and reduced ability to implicitly modulate intensity (Ho et al., 1999b, Ho et al., 2001). Intensity can be modulated if explicit instructions are given (Ho et al., 1999b), suggesting that in part loudness impairments are due to increased effort demands rather than capacity. Reduced loudness has been associated with speech breathing impairments, for example reduced subglottal air pressure, lung air volume expended per

syllable and words per breath group (Solomon and Hixon, 1993, Hammer and Barlow, 2010).

2.4.2.3 Articulation

Impairments of phonological distinctiveness (such as the difference between ‘bark’ and ‘park’ or ‘reed’ and ‘red’) have been found in PD, although results have not been consistent. Studies which found increased (Forrest et al., 1989), decreased (Weismer, 1984) and unaltered (Bunton and Weismer, 2002) voice onset time did not control for speech rate, which has been shown to be an important influence on voice onset time (Miller et al., 1986, Summerfield, 1981). Controlling for rate, Fischer and Goberman (2010) found no overall voice onset time difference between PwPD and controls. However, using another measure of phonemic distinctiveness, the spectral range, Rosen et al (2006) found a significant group effect. Imprecise production of stop and fricative consonants has been identified as one of the most notable markers of PD in perceptual studies (Plowman-Prine et al., 2009, Ackermann and Ziegler, 1991). Acoustically, this has been shown in increased amplitude during stop closure (Ackermann and Ziegler, 1991), reduced /s/ versus /ʃ/ spectral distinctiveness (McRae et al., 2002) and increased nasal airflow as a result of compromised velar-pharyngeal control (Hoodin and Gilbert, 1989).

Studies using the Vowel Space Area (VSA) have yielded equivocal results as to whether PD reduces distinctiveness between the vowels /i/, /u/ and /ɑ/, which constitute the key ‘corner’ vowels of English, especially in an American context. However, VSA relies on absolute vowel formant frequencies rather than ratios. This makes VSA particularly susceptible to individual variation between speakers, both as a result of physical factors such as larynx size and sex effects as well as to socio-cultural factors such as gender and accent. Sapir (2010) demonstrated impaired vowel contrast in PD using ratio-based measures (the F2i/F2u ratio and the Formant Centralization Ratio (FCR), which takes into account both first and second formants of all three vowels). Ratio-based measures are robust to many sources of individual variation.

2.4.2.4 Rhythm

There have been equivocal findings about speech rate in PD (Skodda and Schlegel, 2008, Ludlow et al., 1987, Metter and Hanson, 1986, Caligiuri, 1989). Increased speech acceleration has been found in people with PwPD (Skodda and Schlegel, 2008, Moreau et al., 2007) and associated strongly with festination of gait (Moreau et al., 2007). PwPD have been shown to make significantly fewer but longer between-word pauses and fewer within-word pauses (Skodda and Schlegel, 2008). Studies have shown an increase

in dysfluency (such as pauses, fillers and iterations) associated with PD (Goberman and Blomgren, 2003, Goberman et al., 2010, Benke et al., 2000). Around 30% of PwPD have problematic repetitive speech phenomena, called iterations (Benke et al., 2000).

2.4.2.5 Intelligibility

Studies have demonstrated a reduction in intelligibility associated with PD (Weismer et al., 2001, Miller et al., 2007). Few studies have investigated the relationships between acoustic speech characteristics and intelligibility, and none have provided a thorough comparative overview. Neel (2009) found that Lee Silverman Voice Treatment (LSVT) LOUD[®] speech was more intelligible than amplified speech, suggesting that increased vocal effort may have beneficial effects on intelligibility, besides those directly resulting from increased vocal loudness. Tjaden (2006) also demonstrated an intelligibility benefit of a loud condition. Second formant slope (Weismer et al., 2001, Tjaden and Wilding, 2004), vowel space area (Weismer et al., 2001) and fricative spectral mean (Tjaden and Wilding, 2004) have also been shown to significantly associate with intelligibility. No studies have provided a thorough comparative overview of the relative contributions of a range of acoustic characteristics to speech intelligibility in PD. Moreover, extant studies have tended to focus on subjective rather than objective measures and word rather than sentence intelligibility.

2.4.2.6 Emotional conveyance

PD is associated with reduced pitch variation (see section 2.4.2.1) and facial expression, which may lead to the speech of PwPD being perceived as less emotional. This in turn can lead to negative impressions of personality (Tickle-Degnen and Doyle Lyons, 2004, Pentland et al., 1988, Pentland et al., 1987, Jaywant and Pell, 2010) that do not correlate with the results of formal psychological assessment. PwPD have also been shown to be impaired in perceiving emotion in the speech of others (Benke et al., 1998, Schröder et al., 2006, Möbes et al., 2008). This is believed to be related to impairment of the mesolimbic pathway, which implicates the amygdala, which is a key centre for emotional processing (Schott et al., 2007). Since feedback is recognized to play an important role in speech production (Watkins et al., 2003, van Summers et al., 1988), it is possible that impaired emotion production in PD may be due in part to this emotional perception impairment, in addition to impaired motor speech production. A small study by Miller et al (2008a) found that listeners were less successful in identifying emotions in the speech of PwPD during audio-visual presentation. It was suggested that this finding may result from lack of temporal synchronization between audio and visual cues.

2.4.2.7 Communicative participation

PwPD have been shown to have developed a more negative view of their own communication since the onset of their condition (Miller et al., 2011a, Miller et al., 2008b). PwPD have also reported that their communication has deteriorated, that people treat them less favourably, that conversations are effortful and that they have difficulty being understood in the widest sense (Miller et al., 2006, Walshe and Miller, 2011). Impairments in turn taking, conversation initiation, repair and topic management have been found (Whitworth et al., 1999). Miller et al (2008b) found only a weak association between intelligibility and change in perception of self as a communicator after the onset of PD, with no association with change from baseline to the three-year follow-up. This suggests that psychosocial factors may play a greater role than impairment level factors in everyday communication in PD. Donovan et al (2005, 2007) found that sentence intelligibility scores did not significantly predict communicative effectiveness scores (ICF activity level), although a marginally significant result ($p=0.1$) was found for spontaneous speech intelligibility. In conclusion, the impact of PD on communicative participation has not been studied thoroughly and insufficient dissociation between ICF activity and participation levels has been achieved.

2.4.3 Demographics

Hammer and Barlow (2010) found a significant association between severity of motor speech impairment and overall PD severity. Voice impairments have been consistently associated with overall PD severity (Jiménez-Jiménez et al., 1997, Holmes et al., 2000, Sapir et al., 2001). An association with intelligibility (Miller et al., 2007, Coates and Bakheit, 1997) has also been found. Sapir et al (Sapir et al., 2010) demonstrated that disease duration and UPDRS (Fahn et al., 1987) were associated with increased prevalence of multiple-domain speech impairment (Sapir et al., 2001). UPDRS score associated with self-rated communication difficulties (Miller 2011, 2008). However, no such association was found for Hoehn and Yahr (1967) staging or disease duration.

Gender differences in the impact of PD on speech have been found predominantly with regard to voice. Increased jitter has consistently been found in men with PD (Hertrich et al., 1996, Rahn et al., 2007, Jiménez-Jiménez et al., 1997), whereas women with PD were shown to have reduced jitter and shimmer (Hertrich et al., 1996). In advanced disease, men with PD have been shown to have increased fundamental frequency (Holmes et al., 2000, Gamboa et al., 1997), whereas reduced standard deviation of fundamental frequency has been found in women with PD (Holmes et al., 2000). No

significant impact of gender on the communicative impact of PD has been found (Miller et al., 2008b).

2.4.4 Depression

Few studies have investigated the relationships between depression and speech and communication impairments in PD. Two studies have demonstrated associations between depression and communication. McNamara et al (2010) found that scores indicating high levels of depression, anxiety and stress on the short form of the Depression Anxiety Stress Scales significantly predicted both self- and carer-reported measures of social functioning. Miller et al (2008b) found a statistically significant weak to moderate correlation between depression and a self-report communication questionnaire that asked participants to describe their communication using adjectives. Sapir et al (2001) found that participants with low and high depression scores did not differ significantly on any perceptual speech dimensions. With regard to speech acoustics, Teixeira et al (2012) found no significant difference in speech rate, pause duration and mean intensity in the speech of PwPD with and without depression.

2.4.5 Medication

Studies have reported mixed findings about the effect of dopaminergic medication on the speech of PwPD. Some perceptual, acoustic and intelligibility studies have shown no speech improvements related to dopaminergic medication (Plowman-Prine et al., 2009, Skodda et al., 2010). There is mixed evidence as to whether dopaminergic medication influences voice and prosody in PD (Jiang et al., 1999, Sanabria et al., 2001, Lee and Lin, 2009). The impact on intelligibility is also equivocal (Plowman-Prine et al., 2009, De Letter et al., 2005, De Letter et al., 2007).

2.5 Summary

This chapter initially presented an introduction to PD, before exploring in detail its impact on cognition, speech and communication. Mild cognitive impairment was shown to be prevalent in the early stages of PD. The pathway to dementia was outlined. The chapter concluded by showing how PD can affect a range of aspects of speech and communication, including acoustic characteristics, intelligibility and communicative participation. The following chapter will seek to relate cognitive status with speech and communicative impairment in PD.

Chapter 3: Relationships between cognitive status, and speech and communicative impairments in Parkinson's disease

3.1 Signposting

This chapter presents the results of my systematic review into the relationships between cognitive status, and speech and communicative impairments in PD. It concludes by demonstrating that further investigation of the relationship between cognition status and communicative participation is required. This provides justification for the study presented in the remainder of this thesis.

3.2 Rationale

As detailed in chapter one, impairments of cognition, speech and communication are prevalent in PD. Speech and communication are closely related to cognition. Production and perception of speech rely on interplay of a variety of linguistic levels (McQueen, 2005). Communication relies on understanding other people and the world around us, and planning our communicative input accordingly. This is called social cognition and manifests itself in areas of communication, including conversational maxims, discourse structure, sentence and word choice, and audience effects (Kraut and Higgins, 1984). Therefore, cognitive impairment would be expected to affect speech and communicative performance in PD. A greater impact would be expected for communication, for which the relative influence of social, as opposed to motor factors would be expected to be greater.

I could not identify any systematic or structured literature review that investigated this topic. Therefore, I decided to systematically review extant knowledge about the relationships between cognitive status, and speech and communication impairments in PD. Systematic review is an established scientific method that efficiently integrates and assesses a body of extant evidence in a field, and presents it in a form suitable for clinical decision making (Cook et al., 1997). It seeks to provide greater objectivity than a structured literature review.

3.3 Methods

3.3.1 Search strategy

Owing to the interdisciplinary nature of the topic, I decided to use a wide-ranging search string and database list. I compiled a list of key aspects of cognition, speech, language and communication. I included language terms in this list due to potential lack of specificity of keyword indexing. From this initial list, I developed the Medline search string (Appendix 1). Dr Deane provided peer validation of the search strategy. I then transformed the Medline search string to suit other bibliographic databases.

Since the review topic interfaces with the humanities and social sciences, I decided to search the Web of Knowledge as well as the standard health databases Medline, Embase, Amed and Cinahl. I searched the databases from inception to 30th April 2013. I conducted a supplementary hand search of bibliographies of extracted articles to reduce selection bias. I exported all extracted articles to Endnote X4 (Thomson Reuters, New York).

3.3.2 Study selection

Initially, I assessed all extracted articles on the basis of title and abstract. Subsequently, I sought full-text versions of shortlisted articles for full assessment. Initially I sought articles from the University of East Anglia (UEA). Any article which could not be obtained from UEA, contacts, inter-library loan or the University of Cambridge was excluded from the review.

I decided that full text articles, including brief reports, original book chapters and PhD theses, were required in order to provide sufficient detail to allow thorough data extraction and quality assessment. I determined that conference abstracts would not provide sufficient detail to merit inclusion, unless further detail could be obtained from the authors. I included only original primary research articles and did not consider reviews, editorials or opinion pieces. Since this review summarises a heterogeneous field of investigation, the only methodological criterion that I deemed appropriate to impose was the use of empirical investigation.

Some language restrictions had to be imposed for practical and financial reasons. Due to budgetary restrictions, it was not possible to contract any translation services. I acknowledge that ideally a systematic review should assess all the evidence published worldwide, irrespective of language of publication and that any deviation therefrom represents a selection bias. However, English is regarded as the primary international

language of scientific communication (Maher, 1986, Benfield and Feak, 2006). Additionally, there is evidence of a bias towards English-language articles in bibliographic databases (Van Leeuwen et al., 2001). There is evidence that non-significant results are more likely to be published in languages other than English (Egger et al., 1997), although the meta-analysis was conducted specifically with regard to randomised controlled trials. Jüni et al (2002) found no significant effect of this language bias on the results of systematic reviews. However, I decided to include articles published in languages in which I was sufficiently proficient to conduct rigorous assessment. Therefore, I considered articles published in English, Spanish and German. In order to avoid bias towards particular language families (Gleason, 1961) or cultural contexts, I did not impose any restrictions regarding the language in which the study was conducted.

Due to excessive abstraction, I did not consider studies using animal or computer models of PD. In order to safeguard against anecdotal conclusions, single case studies were not considered for inclusion. I limited the scope of this review to speech and oral communication, and did not include sign-language or written communication. I made this decision to ensure the review was of a manageable size and to ensure direct relevance of the conclusions to my study. Additionally, I only included studies that assessed speech or communication as an outcome measure. For the sake of diagnostic clarity, I only included studies that presented results for PwPD separately from other conditions. Additionally for the sake of rigour, I decided to include only studies that explicitly assessed cognitive status. I defined this as either associating cognitive status with speech or communicative outcome measures or stratifying the sample by cognitive status for analysis. Studies that used tasks which only implied greater cognitive load were excluded. I acted as lead reviewer and Dr Deane provided peer validation.

3.3.3 Data extraction

I entered study characteristics and results from included studies onto standardised characteristic and results tables (see Appendices 2 and 3). All included studies could be described as either cross-sectional (Gerstman, 2013), cohort (Gerstman, 2013), mixed factorial experimental (Richardson et al., 2011) or qualitative (Silverman, 2013). As a result of the diverse methodologies employed, it was not appropriate to conduct statistical meta-analysis.

3.3.4 Quality assessment

I assessed included studies for quality, using a standardised assessment tool based on the instrument of Daley et al (2012). Dr Deane, an author of the assessment

tool publication, provided peer validation. The major advantages of this tool are that it assesses study quality and is methodology-general, whereas more established instruments such as Strengthening the Reporting of Observational Studies in Epidemiology (von Elm et al., 2007) and Consolidated Criteria for Reporting Qualitative Research (Tong et al., 2007) assess predominantly reporting quality rather than study quality and are methodology-specific.

I assessed eight risk of bias items in total. Diagnostic accuracy, participant representativeness and group equivalence were measures of selection bias. Sample size rationale was a measure of chance. Task validity and order effects were measures of detection bias. Appropriate analysis was a measure of detection and reporting bias. Conflict of interest was a measure of reporting bias.

I assessed all quality items through detailed examination of full-text articles. The criteria to be assessed at low risk of bias for each item are outlined below.

For a study to be assessed at low risk of diagnostic inaccuracy, it needed to provide clear criteria as to how PD was assessed. This could be either by listing symptoms or by citing published criteria (Gibb and Lees, 1988, Calne et al., 1992, Gelb et al., 1999). The mention of the term idiopathic was not considered essential. Stating the term 'idiopathic Parkinson's disease' without mentioning criteria was considered insufficient. For a study to be assessed at low risk of participant unrepresentativeness, it had to present an evaluation of its sample and justifiably conclude that the sample was reasonably representative of the target population. For a study to be considered at low risk of group inequivalence, it had to present demographic evidence that the patient and control groups were not sufficiently different in their baseline characteristics to potentially confound interpretation of the study's results.

For a study to be considered at low risk of chance, it had to report a rationale for its sample size. This rationale could be statistically or logically derived.

For a study to be considered at low risk of task invalidity, it had to either cite appropriate published assessments or provide acceptable justification for the tasks used. For a study to be considered at low risk of order effects, it had to state how these were addressed, for example through randomisation or counterbalancing.

For a study to be considered at low risk of inappropriate analysis, it had to state how analysis was conducted and I had to assess this method as suitable. For a study to be considered at low risk of conflict of interest, it had to include a conflict of interest statement which did not include any commercial activities related to the topic of the study.

On occasion, a quality item did not apply to the methods employed in the study, in which case it was marked as not applicable and not counted towards quality assessment. I did not include the attrition bias item suggested by Daley et al (2012) in this review since there were no randomised controlled trials and only one longitudinal study amongst the included studies. In addition, I included an order effects item since this is particularly relevant to methods employed in many studies of speech and communication.

For clarity of presentation, in addition to assessing quality for each item, I assigned a label representing overall risk of bias in the study. I acknowledge that this serves only as a guideline and that cut-offs imposed were essentially arbitrary. Non applicable items were excluded from calculations. Studies with $\geq 70\%$ of items assessed at low risk of bias were considered at overall low risk of bias. Studies with between 50% and 69% of items assessed at low risk of bias were considered at overall moderate risk of bias. Studies with $\leq 49\%$ items assessed at low risk of bias were considered at overall high risk of bias.

In randomised controlled trials, some risk of bias items are evidently more fundamental to overall study risk of bias than other risk of bias items. For example, if randomisation fails, for example due to a technical failure which sees all participants recruited during a particular time period allocated to one arm, the intrinsic quality of the trial is severely compromised. Therefore, it could be argued that a randomised controlled trial which fails on the randomisation risk of bias item should be considered at overall high risk of bias, regardless of results on other risk of bias. Therefore, in the context of randomised controlled trials, the use of unweighted percentage summary indices may not be appropriate.

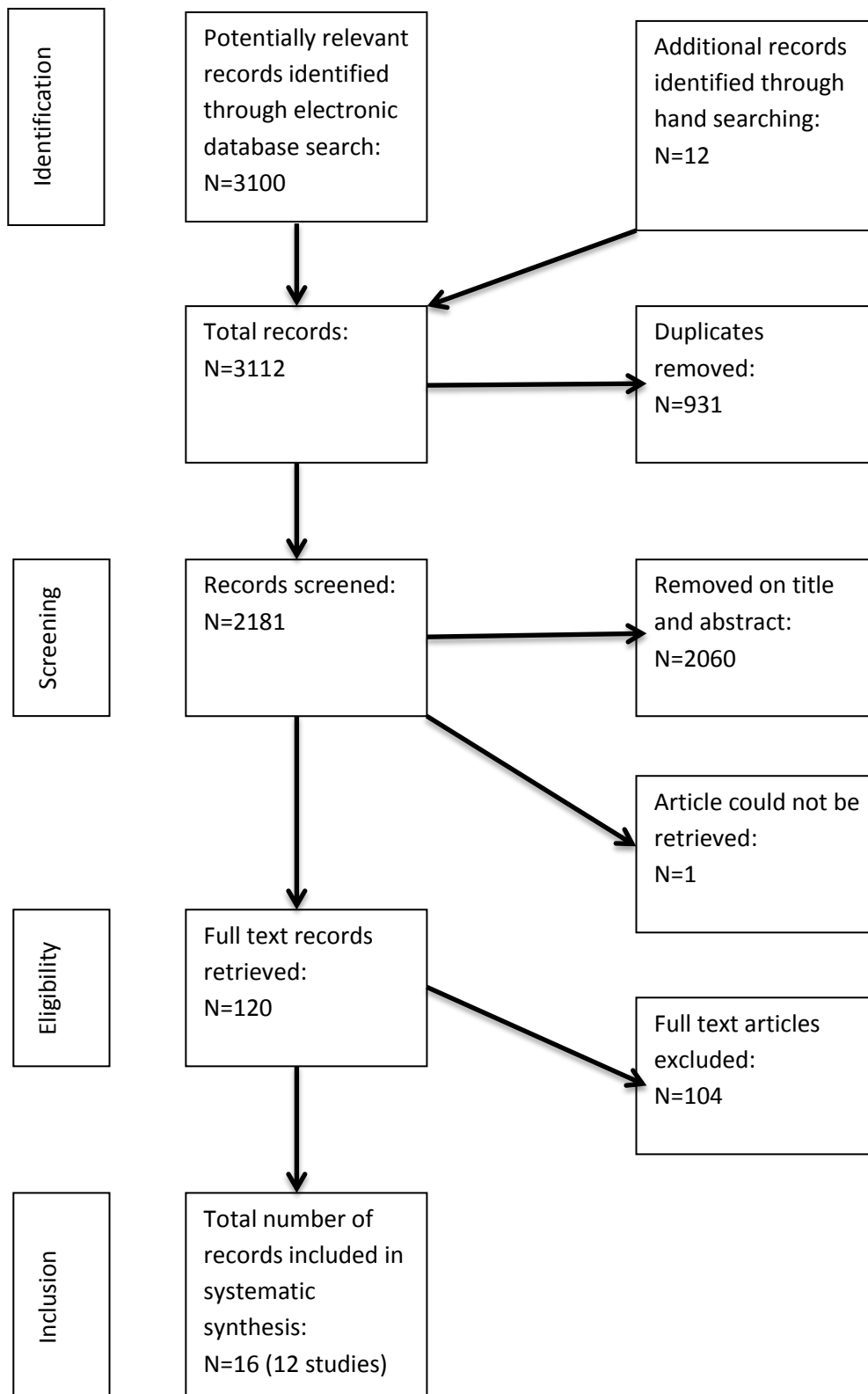
However, my review did not identify any randomised controlled trials meeting the inclusion criteria. Due to the nature of the review question, included studies were either cross-sectional observational, cohort, qualitative or mixed factorial experimental studies, in which any between-participants factors, such as whether the participant had PD or not, were pre-assigned categories. As described above, I adapted the quality assessment tool to suit the requirements of my review. In this review, it was decided that there were no risk of bias items that were more fundamental to overall study risk of bias. Therefore, I deemed it appropriate to use an unweighted percentage summary index of overall study quality.

3.4 Results

3.4.1 Search results

Database searches yielded 3100 results. Twelve additional records were identified through hand searching. Figure 2 shows the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) (Moher et al., 2009) diagram depicting each stage of study identification. After reviewing titles and abstracts, 121 were suitable for full text retrieval. Following thorough evaluation, 16 articles (12 studies) met the inclusion criteria for this review.

Figure 2: PRISMA flow diagram



3.4.2 Summary of included studies

A total of 412 PwPD (57 % male) and 315 controls (48% male) were included in four cross-sectional (Alpert et al., 1990, Hall et al., 2011, McKinlay et al., 2009, McNamara and Durso, 2003), one cohort (Miller et al., 2007, Miller et al., 2011a, Miller et al., 2008b), six mixed factorial (Benke et al., 1998, Breitenstein et al., 2001, Monetta et al., 2008, Dara et al., 2008, Kan et al., 2002, Pell and Leonard, 2003, Yip et al., 2003) and one qualitative (Whitworth et al., 1999, Lesser and Whitworth, 1999) studies. These studies included PwPD who had an overall mean age of 68, 12 years of formal education and disease duration of 6.5 years. Samples were drawn from seven countries worldwide and covered four different languages: English, German, Japanese and Cantonese. These four languages come from three different major language families: Indo-European (Meier-Brügger et al., 2003), Altaic (Miller, 1971) and Sino-Tibetan (Thurgood and LaPolla, 2003). Therefore, a wide variety of different language types are included in the results of this review, which is important for the generalisability of the results.

The median sample size of included studies was 20 PwPD and 20 controls. Four studies recruited at least 30 PwPD per task.

Of the 12 included studies, three (25%) (Miller et al., 2007, Miller et al., 2011a, Miller et al., 2008b, Dara et al., 2008, Monetta et al., 2008, Pell and Leonard, 2003) were considered at low risk of bias. A further three were considered at moderate risk of bias and six at high risk of bias. Of the eight quality domains, the included studies as a whole were rated at low risk of bias with regard to task validity, appropriate analysis and conflict of interest. Moderate ratings were obtained for diagnostic accuracy, group equivalence and order effects.

Table 1: Systematic review threats to validity

Threats to validity	Alpert	Benke	Breitenstein	Dara & Monetta	Hall	Kan	Lesser & Whitworth	McKinlay	McNamara	Miller	Pell	Yip
1 Selection Bias (<u>Diagnostic Accuracy</u>)	?	✓	?	✓	✓	?	✓	?	?	✓	✓	?
2 Selection Bias (<u>Participant representativeness</u>)	?	✓	✗	?	?	?	?	✓	✗	✓	?	✗
3 Selection Bias (<u>Group equivalence</u>)	NA	✓	✓	✓	✗	✗	NA	✓	✗	?	✓	?
4 Chance (<u>Sample size rationale</u>)	?	?	?	?	?	?	?	?	?	?	?	?
5 Detection Bias (<u>Task validity</u>)	✓	?	✓	✓	✓	?	✓	✓	✓	✓	✓	✓
6 Detection Bias (<u>Order effects</u>)	?	?	✓	✓	?	✓	?	?	?	✓	✓	✓
7 Detection/ Reporting Bias (<u>Appropriate analysis</u>)	?	✓	✓	✓	?	✓	?	✓	✓	✓	✓	✓
8 Reporting Bias (Conflict of interest)	?	?	✓	✓	?	✓	✓	✓	?	✓	✓	?
Quality Summary	H	M	M	L	H	H	H	M	H	L	L	H

✓ = low risk of bias, ✗ = high risk of bias, ? = unclear, NA = not applicable to study, H = high risk of bias, M = moderate risk of bias, L = low risk of bias

Table 2: Systematic review findings about extant knowledge between cognitive status, and speech and communication impairments in Parkinson's disease

Theme	Study	Language	Design	Study N	Total N	PD vs control	Cognition	Risk of bias
<u>1) Pragmatics</u>	Dara & Monetta	English	M factorial	PD:16, CON:17	PD:93,CON:84	Yes	Yes	Low
	McKinlay	English	X-sectional	PD:40, CON:40		Yes	Yes	Moderate
	McNamara	English	X-sectional	PD:20,CON:10		Yes	Yes	High
	Hall	English	X-sectional	PD:17,CON:17		Yes	Yes	High
<u>2) Intelligibility</u>	Miller	English	Cohort	PD:125,CON:40	PD:125,CON:40	Yes	Yes	Low
<u>3) Prosodic perception</u>	Breitenstein	English	M factorial	PD:20, CON:16	PD:177,CON:150	Yes	Yes	Moderate
	Benke	German	M factorial	PD:48, CON:18		Yes	Unclear	Moderate
	Yip	Cantonese	M factorial	PD:56, CON:56		Yes	No	High
	Pell	English	M factorial	PD:21, CON:21		Unclear	Yes	Low
	Dara & Monetta	English	M factorial	PD:16, CON:17		Unclear	No	Moderate
	Kan	Japanese	M factorial	PD:16, CON:22		No	No	High
<u>4) Conversation management</u>	Lesser & Whitworth	English	Qualitative	PD:12	PD:22	NA	Yes	High

	Alpert	English	X-sectional	PD:10		NA	Yes	High
<u>5)Communicative participation</u>	Lesser & Whitworth	English	Qualitative	PD:12	PD:116	NA	Yes	High
	Miller	English	Cohort	PD:104		NA	No	Low
<u>6)Acoustics</u>	Alpert	English	X-sectional	PD:10	PD:58, CON:18	NA	Yes	High
	Benke	German	M factorial	PD:48, CON:18		Yes	Unclear	Moderate

M factorial=mixed factorial, X-sectional=cross sectional

3.4.3 Pragmatics

Pragmatics refers to how context contributes to meaning. Four studies were identified that investigated the impact of cognitive impairment on pragmatics in PD (Monetta et al., 2008, Hall et al., 2011, McKinlay et al., 2009, McNamara and Durso, 2003). They had a combined sample size of 93 PwPD and 84 controls. One study (Monetta et al., 2008) was assessed at low risk of bias, one (McKinlay et al., 2009) at moderate risk of bias and two (Hall et al., 2011, McNamara and Durso, 2003) at high risk of bias. All four studies found that PwPD were significantly impaired in pragmatics compared to controls and found evidence for a contribution of cognitive impairment. Monetta et al (2008) found that only PwPD with impaired working memory performed below the level of controls on the Discourse Comprehension Test (Brookshire and Nicholas, 1997). Additionally, there was a significant positive association between verbal memory and performance on inference and detailed questions. McKinlay et al (2009) found that PwPD were impaired on the Test of Language Competence- Expanded (Wiig and Secord, 1989), overall and on the making inferences, oral expression and figurative language sub-tests. Test of Language Competence- Expanded scores were associated significantly with span, information processing speed and attention-shifting. Hall et al (2011) found that PwPD were significantly impaired on the Rating Scale of Pragmatic Communication Skills, performance associating significantly with MMSE scores. McNamara and Durso (2003) found that PwPD were significantly impaired on a pragmatic protocol. Performance correlated significantly with measures of attention and planning.

Pragmatics is the area of speech and communication impairment in PD for which there is currently the strongest evidence of an association with cognitive status. Since pragmatics relates to the use of meaning in context, pragmatic impairment could make a PwPD appear socially awkward and even rude, through for example a failure to understand humour and to modify language expression depending on the conversational situation.

3.4.4 Intelligibility

One large high quality study was identified that investigated the impact of cognitive impairment on intelligibility in PD (Miller et al., 2007). PwPD were found to have reduced self- and listener-rated intelligibility. MMSE score was a significant predictor of listener-rated intelligibility. Intelligibility was rated as the area with the second strongest available evidence of an association with cognitive impairment, due to the size and quality of the included study. This suggests that the more cognitive impairment PwPD have, the more difficult it is to understand their speech. However, replication of these findings in a different locality would strengthen the evidence base.

3.4.5 Prosodic perception

Six studies were identified that investigated the impact of cognitive impairment on the perception of prosody by PwPD (Benke et al., 1998, Breitenstein et al., 2001, Dara et al., 2008, Pell and Leonard, 2003, Kan et al., 2002, Yip et al., 2003). All studies investigated emotional rather than grammatical prosody. Emotional prosody refers to how speakers communicate intended emotion through the melody and rhythm of speech. Grammatical prosody refers to how speakers communicate grammatical functions, such as emphasis or the difference between a statement and a question, through the melody and rhythm of speech. These studies had a combined sample size of 177 PwPD and 150 controls.

One study (Pell and Leonard, 2003) was assessed at low risk of bias, three (Benke et al., 1998, Breitenstein et al., 2001, Dara et al., 2008) at moderate risk of bias and two (Kan et al., 2002, Yip et al., 2003) at high risk of bias. Benke et al (1998), Breitenstein et al (2001) and Yip et al (2003) found that PwPD were significantly impaired in their recognition of emotional speech. Kan et al (2002) found no such difference. Dara et al (2008) found that PwPD were impaired in emotional prosody recognition only in the absence of congruent verbal cues. Pell and Leonard (2003) found a marginally significant result for impaired recognition of well-formed sentences, with a significant effect in nonsense sentences.

Executive function, in particular auditory working memory, was shown to associate with emotional prosody recognition. Whereas Breitenstein et al (2001) and Pell and Leonard (2003) found this relationship for well-formed or congruent sentences as well as nonsense or incongruent sentences, Dara et al (2008) only found this association for nonsense sentences. Breitenstein et al (2001) found that the contribution of executive function was greater in the incongruent condition. Span (Yip et al., 2003) and MMSE (Kan et al., 2002, Breitenstein et al., 2001) scores did not associate significantly with emotional speech recognition. Benke et al (1998) found that only PwPD who had impaired working memory were impaired in emotional prosodic recognition. However, performance did not significantly associate with cognitive measures. There is moderate evidence that PwPD can be impaired in aspects of emotional prosody recognition, and that this appears to be associated with executive function. However, further large scale high quality studies are required to clarify these relationships. Impaired perception of emotional prosody would mean that PwPD would be less able to perceive intended emotion in the speech of others. In addition, no included studies investigated the impact of cognitive impairment on the perception of grammatical prosody. Impaired perception of grammatical prosody would

mean that PwPD could misidentify sentence emphasis or whether a sentence was intended as an order, a statement or a question. High quality studies are required to assess this aspect of prosodic perception.

3.4.6 Conversation management

Two studies were identified that investigated the relationship between cognitive impairment and conversation management abilities in PD (Lesser and Whitworth, 1999, Alpert et al., 1990, Whitworth et al., 1999). They had a combined sample size of 22 PwPD and no controls. Both studies were assessed at high risk of bias. Neither study assessed the difference in conversation management ability between PwPD and controls. Lesser and Whitworth (1999) and Whitworth et al's (1999) study found that PwPD with 'sub-cortical dementia' did not differ overall on conversation analysis parameters from those with Lewy body dementia, although they did have more difficulty orientating the conversation partner (CP) to a new topic. Alpert et al (2001) found that cognitive impairment was negatively associated with conversation interruption. Extant evidence for an association between cognitive status and impaired conversational management in PD is weak. There is a need for larger high quality studies with a control group, to clarify that conversation management impairments exist and how they relate to cognitive impairment.

3.4.7 Communicative participation

Two studies were identified that investigated the impact of cognitive impairment on communicative participation in PD (Whitworth et al., 1999, Miller et al., 2011a, Miller et al., 2008b). They had a combined sample size of 127 PwPD and no controls for the tasks relevant to this theme. One study (Miller et al., 2011a, Miller et al., 2008b) that contributed 104 participants, was assessed at low risk of bias, whereas the other (Whitworth et al., 1999) was assessed at high risk of bias. Neither study assessed the difference in communicative participation between PwPD and controls. Whitworth et al (1999) found that people with Lewy body dementia retained fewer pre-morbid communicative situations than PwPD and 'subcortical dementia'. However, Miller et al (2011a, 2008b) found that MMSE score did not predict change in self-rated communication score at follow-up. However, this finding could be explained by the relative insensitivity of the MMSE to mild cognitive impairment in PD (Hoops et al., 2009, Gill et al., 2008, Mamikonyan et al., 2009) and the fact that the questionnaire used assessed changes in people's descriptions of their own communication using adjectives rather than directly assessing the impact of PD on their participation in everyday communication.

Currently, there is no substantive evidence of a relationship between cognitive status and communicative participation in PD. However, due to the theoretical grounds for expecting such an association as described in section 2.1, this relationship merits further study using a more sensitive cognitive assessment and a communication questionnaire which probes participation in everyday activities.

3.4.8 Acoustics

Two studies were identified that investigated the impact of cognitive status on the speech acoustics of PwPD (Alpert et al., 1990, Benke et al., 1998). Both investigated prosody. They had a combined sample size of 58 PwPD and 18 controls. One study (Benke et al., 1998) was assessed at moderate risk of bias and one study (Alpert et al., 1990) at high risk of bias. Alpert et al (1990) found that a composite dementia scale was significantly negatively associated with the frequency of internal pauses, and positively associated with mean internal pause length. Therefore, PwPD who had more cognitive impairment paused less but these pauses were of greater duration. However, the study was assessed at high risk of bias and did not compare PwPD with controls. Benke et al (1998) found that only PwPD who had impaired working memory were impaired in the production of emotional prosody. In correlational analyses, digit symbol substitution was the only cognitive measure which significantly associated with emotional prosody production. The effect of cognition on prosodic production in PD remains equivocal and its effect on other acoustic characteristics of speech uninvestigated. Further high quality research is required to establish these relationships.

3.5 Discussion

This review shows that extant knowledge regarding the relationships between cognitive status, and speech and communicative impairments in PD is limited with regard to methodological quality and the aspects of speech and communication which have been investigated. However, there is at least preliminary evidence for an association between aspects of cognitive impairment, and domains of speech and communicative functioning (henceforth called 'domains').

There was moderate evidence for an association between cognitive status and three domains. These were pragmatics, intelligibility and prosodic perception. In the pragmatic domain, PwPD with greater cognitive impairment had more difficulty answering detailed questions (Monetta et al., 2008), making inferences (Monetta et al., 2008, McKinlay et al., 2009) and using figurative language (McKinlay et al., 2009). Impaired

general pragmatic communication skills were found by Hall et al (2011) and McNamara and Durso (2003). It must be noted that McNamara and Durso's pragmatic protocol included some items which relate more to conversation management. However, the protocol produces a single composite score and I decided it was more appropriate to assign it to the pragmatics domain.

In the intelligibility domain, listeners were shown to have more difficulty understanding the speech of PwPD who had greater cognitive impairment (Miller et al., 2007). This was a large study which was assessed at low risk of bias.

In the domain of prosodic perception, included studies investigated only the perception of emotional rather than grammatical prosody. Therefore, it remains unclear whether the impact of cognitive status on the perception of prosody by PwPD is specific to emotional stimuli. Some studies (Dara et al., 2008, Pell and Leonard, 2003, Kan et al., 2002) did not show a statistically significant difference between the emotional prosody perception of PwPD and controls, when well-formed sentences were presented. Benke et al (1998), Breitenstein et al (2001) and Yip et al (2003) however found this difference. There was greater evidence for a role of executive function, in particular auditory working memory, when the emotional stimuli presented to PwPD were either linguistically incongruent or nonsense sentences (Dara et al., 2008, Breitenstein et al., 2001). Breitenstein et al (2001) and Pell and Leonard (2003) did however find associations between executive function and perception of well-formed emotional stimuli. Studies (Yip et al., 2003, Kan et al., 2002, Breitenstein et al., 2001) provided evidence that more general cognitive measures and span did not associate with emotional prosodic perception. Greater emotion perception impairment for linguistically incongruent sentences could mean that PwPD could, for example, have difficulty in perceiving intended emotion in conversations shortly after a change of topic.

There was weak evidence for an association between cognitive status and three domains. These were conversation management, communicative participation and acoustics. In the domain of conversation management, no included study compared the abilities of PwPD with controls. A study by Whitworth and Lesser (Lesser and Whitworth, 1999, Whitworth et al., 1999) found an association between cognitive status and aspects of conversation management. However, it did not find any widespread differences in conversation management ability. These studies were assessed as being at high risk of bias.

In the domain of communicative participation, there have been inconsistent results regarding the role of cognitive status. Whitworth et al (1999) found that people with Lewy

body dementia retained fewer pre-morbid communicative situations than people with PD and 'subcortical dementia'. However, Miller et al (2011a, 2008b) found that MMSE score did not predict change in self-rated communication score at follow-up. Moreover, neither study compared the communicative participation of PwPD and controls.

In the acoustic domain, both included studies assessed prosody. No included study investigated the association between cognitive status and acoustic speech characteristics in non-emotional read or conversational sentences. PwPD with greater cognitive impairment were shown to have fewer and longer internal pauses (Alpert et al., 1990) and impaired emotional prosodic production (Benke et al., 1998). However, relationships with cognitive measures were inconsistent in Benke's study. Moreover, both studies were assessed as being at high risk of bias.

It is notable that extant evidence appears stronger for the Impairment than Activity or Participation ICF levels. Of the three domains for which there is moderate evidence, intelligibility and prosodic perception are at the Impairment level, whereas pragmatics is at the Activity level. Of the three domains for which evidence is weak, acoustics is at the Impairment level, conversation management at the Activity level and communicative participation at the Participation level.

However, this does not necessarily imply that the impact of cognitive status on the Activity and Participation levels is less profound than the impact on the Impairment level. It may be merely an artefact of the number and quality of studies that investigated each ICF level. Of the 12 studies included in this review, eight investigated the Impairment level, six the Activity level and two the Participation level. Some studies contributed to more than one ICF level.

Of the eight Impairment level studies, three (38%) (Miller et al., 2007, Dara et al., 2008, Pell and Leonard, 2003) were assessed at low risk of bias, two (25%) (Breitenstein et al., 2001) (Benke et al., 1998) were assessed at moderate risk of bias and three (38%) were assessed at high risk of bias. Of the six Activity level studies, one (17%) (Dara et al., 2008) was assessed at low risk of bias, one (17%) (McKinlay et al., 2009) was assessed at moderate risk of bias and four (67%) were assessed at high risk of bias. Of the two Participation level studies, one (50%) (Miller et al., 2011a, Miller et al., 2008b) was assessed at low risk of bias and one (50%) (Whitworth et al., 1999) was assessed at high risk of bias.

From these statistics, it is evident that the Participation level has been under researched in terms of the number of studies. Furthermore, the quality of activity level studies has been low. The quantity and quality of Impairment level studies has been

highest. Therefore, the fact that extant evidence for an association between cognitive status, and speech and communicative impairments in PD is strongest for the Impairment level may reflect study relative quantity and quality in the three ICF domains, rather than implying that the impact of cognitive status is greatest on the Impairment level.

This review demonstrates that there is overall moderate evidence for an association between cognitive status, and speech and communicative impairments in PD. Extant evidence is moderate for pragmatics, intelligibility and production of emotional prosody. There is weak evidence for conversation management, communicative participation and acoustics. No included studies investigated the perception of grammatical prosody or the production of speech acoustics in non-emotional sentences. Few studies investigated the ICF Participation level. The ICF Activity level was an area where studies were of particularly low methodological quality.

Many included studies exhibited significant methodological limitations. I shall give a few examples here. Three (25%) studies did not include a non-PD control group for at least some tasks. Three (25%) studies only used the MMSE as a measure of cognitive status. As discussed above, this has been shown to be relatively insensitive to mild cognitive impairment in PD as a measure of cognitive status. However, since MMSE is a validated scale, this did not count against the task validity criterion of the quality assessment tool. Only three (25%) studies were assessed at low risk of participant unrepresentativeness, mainly because six (50%) studies did not provide any evidence on which to base this assessment. Only five (50%) studies involving group comparisons were assessed at low risk of group inequivalence.

Only one (8%) study (Miller et al., 2011a, Miller et al., 2008b) included longitudinal results for some tasks. While longitudinal designs are not suitable for every investigation, they have the advantage of providing a time sequence of events, which aids the interpretation of causation (Richardson et al., 2011, Gerstman, 2013). However, as seen in Miller's study, in which only 26% of participants completed the communicative questionnaire at the three year follow-up, longitudinal designs are vulnerable to attrition bias (Richardson et al., 2011). This review included no longitudinal studies using an incident cohort. When participants entering a study differ in terms of disease severity, there is an incidence-prevalence bias (Neyman, 1955) which confounds the interpretation of causality (Gerstman, 2013).

Although many studies in this review exhibited significant methodological limitations, there were some methodological strengths to the included studies. The fact that the four languages investigated come from three different language families

increases the generalisability of results. It provides evidence that the conclusions drawn are not merely an artefact of the languages sampled. Five (42%) studies used what I considered a relatively thorough neuropsychological assessment in at least some tasks. I did not apply the MDS level two mild cognitive impairment criteria (Litvan et al., 2012) for determining what constituted a thorough neuropsychological assessment, since all of included studies were conducted prior to the publication of the MDS criteria.

This review found moderate evidence for an impact of cognitive status on intelligibility and the perception of emotional prosody in PD. No included studies assessed the impact of cognitive status on the perception of grammatical prosody by PwPD. This prevents definitive assessment of whether the prosodic perception impairment in PD is emotion-specific. The mesolimbic system, which is one of the dopaminergic pathways implicated in PD passes through the limbic system on its way from the midbrain to the frontal cortex (Schott et al., 2007). Limbic structures such as the amygdala have been shown to be important for emotion (Fitzgerald et al., 2006) and reward (Schott et al., 2007). Therefore, in addition to impaired general cognition, there is the potential for emotion-specific impairments in PD.

However, there are two types of literature which could help evaluate to what extent the contribution of cognitive status to impaired perception of prosody by PwPD is likely to be specific to emotional stimuli. Firstly, there are studies that investigated the perception of emotion by PwPD, but were excluded from this review, because the role of cognitive status was not assessed explicitly. Scott et al (1984) and Ariatti et al (2008) found that PwPD were impaired in the perception of grammatical prosody. However, no such group difference was found by Pell (1996), Darkins et al (1988) or Lloyd (1999). Although these results are not conclusive, they suggest that impaired perception of prosody by PwPD is not restricted to emotional stimuli. They do not explicitly assess the role of cognitive status.

Secondly, there are studies and tasks that investigated the perception of emotion by PwPD, but were excluded from this review, because pictorial rather than auditory stimuli were used. Jacobs et al (1995), Kan et al (2002) and Dujardin et al (2004), for example, all found evidence of significantly impaired perception of emotional pictorial facial stimuli by PwPD. Dujardin et al (2004), but not Kan et al (2002), found a significant association with cognitive status.

These findings suggest a potential emotion-specific impairment and clarify that emotional perception impairments in PD are not specific to the prosodic domain. These two groups of papers show that prosodic impairments are not only found in the emotional

domain, and that emotional impairments are not only found in the prosodic domain. The mechanisms of action remain unconfirmed. However, it is possible that these observed deficits relate to a mixture of emotion-specific impairments resulting from impaired mesolimbic circuitry, and more general cognitive impairments resulting from impaired mesocortical and mesolimbic circuitry.

Impairments of the acoustic characteristics of speech and intelligibility have traditionally been associated almost exclusively with motor speech impairment. Potentially, this is the reason why few studies investigating these domains were identified. Three additional studies were identified that assessed prosodic speech acoustics. However, two of these did not meet the criterion of explicit assessment of cognitive status and the other did not meet the criterion of an aspect of speech or communication being an outcome measure. As described above, moderate evidence was found of an association between cognitive status and intelligibility in PD (Miller et al., 2007). However, although this study was large and assessed as at low risk of bias, replication and extension in other settings would strengthen the evidence that speech intelligibility in PD may not rely exclusively on motoric mechanisms. No included studies investigated non-prosodic acoustic speech characteristics. Two included studies (Alpert et al., 1990, Benke et al., 1998) investigated prosodic acoustic speech characteristics. Alpert et al (1990) did not assess for a difference between PwPD and controls, and was assessed as at high risk of bias. Benke et al (1998), which was assessed as at moderate risk of bias, found that only PwPD who had impaired working memory were impaired in emotional prosodic production relative to controls. Correlation analyses with cognitive measures were equivocal. These studies do not offer substantive evidence for a role of cognitive impairment in impaired prosodic acoustic speech characteristics in PD. However, in the light of Miller et al's (2007) finding with relation to intelligibility, further studies of a wider range of acoustic speech characteristics could clarify whether there may be a cognitive component to speech production impairments in PD, which have been traditionally associated with motoric impairments.

"A social being has one prime need- to communicate" (Douglas and Ney, 1998c). Therefore communicative deficits threaten to undermine a key human function. Miller et al (2006) found that PwPD were not predominantly concerned about impairment level changes in their speech, but rather how these affected their self-concept and participation in everyday communicative situations. Further studies are required to establish definitively the extent to which Impairment and Participation level measures of speech and communication associate. It is likely that reduced communicative participation in PD

relates partly to physical speech impairments and partly to psychosocial factors (see sections 2.4.2.5 and 2.4.2.7).

The impact of PD on communication is relevant to all healthcare professionals who treat PwPD. There is international evidence from several studies that speech and communication impairments in PD affect the patient-practitioner relationship. Pentland et al (1987) found that Scottish health professionals watching silent videos judged PwPD to be less intelligent and to have a more negative personality than cardiac patients, even though these judgements did not associate with the results of standardised psychological tests. Tickle-Degnen and Doyle Lyons (2004) found that American healthcare professionals' judgements of personality were overly affected by reduced facial expression in PD, this effect being stronger in novice practitioners. Mott et al (2004a) found that Australian PwPD reported loss of facial expressiveness to be more troublesome than difficulty being understood or swallowing. Participants reported they felt that non-specialist healthcare professionals often didn't fully understand what it was like to have the condition.

This review found moderate evidence for a role of cognitive status in pragmatic communication impairments in PD. However, as described above, only weak evidence was found for its effect on conversation management and communicative participation, potentially due to methodological limitations of extant studies.

The DSM-5 criteria (APA, 2013) for neurocognitive disorders acknowledge social cognition as one of six cognitive domains, alongside complex attention, executive function, learning and memory, language and perceptual-motor function. Social cognition is essential for successful communication. Communication requires understanding the other participants, including their status, background and prior knowledge (Kraut and Higgins, 1984). According to Grice (1975), the basic rule of conversation is mutual co-operation. It also involves an appreciation of socio-normative conversational maxims (Clark and Clark, 1977). Moreover, communication draws upon other aspects of cognitive function. Conversations require planning and set-shifting to tailor each stage of discourse to the communicative situation (Kraut and Higgins, 1984). Therefore, one would expect impaired cognitive status to affect everyday communication.

However, commonly used cognitive assessments seldom include social cognition and it is not established how social cognition relates to global cognitive function. In contrast to the DSM-5 criteria for neurocognitive disorders (American Psychiatric Association, 2013), the MDS criteria (Litvan et al., 2012) for mild cognitive impairment in PD do not include social cognition. The MDS criteria propose five cognitive domains,

which are attention and working memory, executive function, language, memory and visuospatial function. With the exception of some minor grouping differences, these two domain systems are relatively similar, except for the omission of social cognition from the MDS criteria.

Given that moderate evidence for an association with cognitive status was found for one aspect of social communication, that is pragmatics, where studies were superior in terms of quantity and quality, it is likely that the lack of substantive evidence for an impact on conversation management and communicative participation relates to a lack of studies and methodological issues. With regard to communicative participation, the selection of outcome measures has been problematic. Whitworth and Lesser's (Lesser and Whitworth, 1999, Whitworth et al., 1999) measure, in terms of the proportion of pre-morbid communicative situations retained, is a measure of the ICF Participation level. However, while it has face validity as a participation measure, it is rather superficial. The outcome measure used in Miller et al's (2007) study asked participants to report how they viewed themselves as communicators using a seven-point semantic differential questionnaire. While the measure was derived from literature searches, it does not appear to have been validated prior to use. Moreover, it does not sufficiently dissociate the ICF Participation and Activity levels.

Further research is indicated into the impact of cognitive status on communicative functioning in PD. High quality studies are required to strengthen the evidence for an association between cognitive status and conversation management. Moreover, further research is particularly required into the impact of cognitive status on participation. Future research into communicative participation needs to use more sensitive cognitive instruments, which provide a more subtle cognitive profiling than merely in terms of the presence or absence of dementia. Neuropsychological batteries could be used to disambiguate which aspects of cognitive function are most important for communicative participation. The role of social cognition also merits attention. In order to categorically establish the time course of the emergence of cognitive and communicative impairments, and provide greater ability to infer causation, communication should be embedded into a longitudinal natural history study of incident PD.

3.6 Summary

This chapter initially provided a rationale for undertaking a systematic review of extant knowledge of the relationships between cognitive status, and speech and communicative impairments in PD. It then proceeded to detail and justify the search strategy employed. It presented and discussed the results of the review. These concluded

that while there is some preliminary evidence of relationships between aspects of cognitive status, speech and communicative impairment in PD, further high quality research is indicated to clarify these relationships. The following chapter will introduce and justify my research questions, methodological frameworks and principal data collection methods.

Chapter 4: Research questions and methods

4.1 Signposting

This chapter starts by introducing my research questions. It then proceeds to establish the methodological frameworks that I used in my study. It explores the recruitment process including the various options I considered and why I decided on the strategy I used in the study. It provides a rationale for the principal data collection methods and assessments I used in my study. Finally, it addresses ethical considerations in the study design.

4.2 Rationale and aims

4.2.1 Statement of key research questions

My primary research question was:

- 1) How does cognitive status associate with the communicative effectiveness and communicative participation of PwPD? (Questionnaire analysis)

My secondary research questions were:

- 2) How do PwPD and CPs differ in terms of the acoustic characteristics of their read and conversational speech? (Phonetic analysis)
- 3) How does cognitive status contribute to these acoustic characteristics? (Questionnaire analysis and phonetic analysis)
- 4) How do these acoustic differences contribute to intelligibility? (Phonetic analysis and listener analysis)
- 5) How do PwPD and CPs differ in terms of the acoustic correlates of happy, sad and neutral speech? (Phonetic analysis)
- 6) How does cognitive status contribute to these acoustic characteristics? (Questionnaire analysis and phonetic analysis)
- 7) How do these acoustic differences contribute to emotional conveyance? (Phonetic analysis and listener analysis)
- 8) How does intelligibility associate with the communicative effectiveness and communicative participation of PwPD? (Questionnaire analysis and listener analysis)
- 9) How do PwPD view their own speech and communication? (Qualitative Content Analysis)

4.2.2 Rationale

PD is a common neurodegenerative condition, which has been shown to have widespread impact on employment, quality of life and mortality (see section 2.2.1). Studies have shown that PD often affects cognitive status, even in the early stages of the disease pathway. Mild cognitive impairment in PD frequently progresses to dementia (see section 2.3.1.4). PD has been shown to affect a wide range of acoustic speech characteristics and result in reduced intelligibility. PwPD have been shown to be impaired in their production and perception of emotion. It is also known that PD often affects communicative participation (see section 2.4.2.7).

However, there are significant limitations to extant studies and many key relationships have not been investigated thoroughly (see chapter 3). No British studies of relationships between cognitive status and the speech acoustics of people with PD could be identified. It is important to replicate and extend the findings of studies conducted in other languages and in other varieties of English, since varieties of English differ significantly in their acoustic characteristics (see section 4.6.1). No thorough investigation of the relationships between speech acoustics, and intelligibility and emotional conveyance in PD could be identified. Extant knowledge of the relationships between cognitive status and acoustic speech characteristics in PD is limited (see chapter 3).

Few studies have investigated relationships between cognitive status and communicative effectiveness and participation in PD (see chapter 3). Studies have exhibited limitations with regard to cognitive profiling and outcome measure selection. In addition, no identified study has provided an overview of the pathway from cognitive status, through speech impairment to reduced communicative activity and participation (see Figure 1).

4.3 Methodology

4.3.1 A cross-sectional observational design

In this study, my primary methodology was a quantitative cross-sectional observational design. Quantitative research has its origins in the philosophy of positivism. Positivism claims that valid knowledge can only come from scientific and mathematical enquiry (Colman, 2006). It rejects the validity of introspection and intuition. Positivism was first explicitly formulated by August Comte in 1865 (Comte, 2009), although the philosophy draws on the earlier work of Henri de Saint-Simon and Francis Bacon (Colman, 2006, Pickering, 1993). Postpositivism has refined this stance to accept that the

researcher can influence observations and that reality can only be held imperfectly and probabilistically. It is debated whether Sir Karl Popper (Popper, 1965) or Thomas Kuhn (Kuhn, 1970) should be regarded as more influential in the development of postpositivism. The study presented in this thesis falls broadly under the postpositivist philosophy.

Quantitative designs primarily seek to answer questions of fact ('what' questions), such the prevalence of phenomena and relationships between variables (Richardson et al., 2011). In my study, I primarily sought to investigate the relationships between cognitive status, speech impairment and communicative participation in PD. Therefore, quantitative methods were best suited as the base design for this study.

The optimal design for the assessment of cause and effect is a true experimental design, in which all independent variables are manipulated by the investigator (Richardson et al., 2011). However, in studies like the present investigation, key independent variables, such as cognitive status, cannot ethically be manipulated in human participants. When experimental designs are not possible (Gerstman, 2013), observational designs must be used. An observational design seeks to observe but not influence participant characteristics and behaviours (Gerstman, 2013, Vanderstoep and Johnson, 2009). Therefore, they offer more limited interpretation of causal relations. Indeed, some theorists deem it a fallacy to make any causal inferences based on correlational data (Gould, 1996, Matthews, 2000).

Observational designs can be longitudinal or cross-sectional. Both of these approaches have their respective strengths and weaknesses. Longitudinal investigations are very expensive, pose challenges regarding random baseline sampling and researcher continuity, and are subject to selective attrition and maturation effects (Richardson et al., 2011). However, they allow analysis over time at the group and individual level (Richardson et al., 2011), and this clearer time course allows greater causal inference (Gerstman, 2013).

Cross-sectional studies can be subject to greater detection, diagnostic, reverse-causality and incidence-prevalence biases (Gerstman, 2013). They do not offer definitive explanation of group differences (Richardson et al., 2011). However, they are not subject to attrition, researcher continuity and maturation effects, are considerably less resource-demanding and are often more feasible to conduct (Richardson et al., 2011).

I decided to use a cross-sectional observational design as the basis for my investigation. As described above, a true experiment was not feasible due to the nature of my investigation. A longitudinal design was not possible within the time and resource limitations of a doctorate. Despite certain limitations outlined above, I decided that a

cross-sectional observational design would offer a suitable means of investigating the relationships between cognitive status, speech impairment and communicative participation in PD.

4.3.2 Embedding a within-participants element

The listener assessment exercise used in my study (see section 5.5) involved embedding a within-participants design (Richardson et al., 2011) into the analysis of my cross-sectional observational design. This design can also be called a within-subjects design (Goodwin, 2010), within-groups design (Coolican, 2006) or repeated measures design (Coolican, 2006, Shaughnessy et al., 2012). Although these terms are more commonly used in psychological research than medical research, randomised controlled trials combine between-participant (treatment allocation) and within-participant (serial measurement time points) factors.

For example, in the emotional conveyance task (see section 5.5.3.2), assessors were presented with stimuli which differed in terms of speaker group (PD versus CP), mood (happy, sad or neutral) and modality (audio versus audio-visual). Each of these represents an experimentally manipulated within-participants factor. Speaker group is seen as a within-participants factor, since the listeners are defined as the 'participants' in the listener assessment from a research design point of view. However, from an ethical approval point of view, PwPD and CPs were seen as participants and listeners were seen as researchers.

A within-participants design requires fewer participants (Shaughnessy et al., 2012, Goodwin, 2010) and is generally more powerful (Evans and Rooney, 2011) than a between-participants design, since it eliminates the participant variable between levels of independent variables (Coolican, 2006, Richardson et al., 2011, Shaughnessy et al., 2012). However, it is subject to potential order and practice effects (Coolican, 2006, Evans and Rooney, 2011, Goodwin, 2010, Richardson et al., 2011, Shaughnessy et al., 2012). These are discussed in section 5.5.3.

I decided to use a within- rather than between-participants design for listener assessment. It reduced the amount of assessors I had to recruit to provide the same quantity of data. The assessment session was also relatively short. A between-subjects design would have also required more time in the laboratory, which is often used for teaching, so reducing its availability for my research. However, beyond practicalities, a within-participants design offered significant methodological advantages to my listener assessment. It eliminated the participant variable that would have existed had two groups

of listeners been used. It also generated more data and offered more statistical power for the same number of assessors.

4.3.3 Embedding a qualitative element

As discussed in section 4.5, many participants provided detailed accounts about the acceptability of the Communicative Participation Item Bank (CPIB) and wider issues of speech and communication, which exceeded the level of detail I had expected. Research with human beings always involves an element of unpredictability (Cziko, 1989) and it is important to respond to participant wishes. It would be unethical to waste these data, which could firstly provide a valuable insight into participants' experiences of speech and communicative impairment and secondly provide a participant's eye view of the acceptability of the CPIB. It was agreed that secondary analysis of anonymised already collected data did not require an ethics amendment.

Once it had been decided that analysis of these comments would be performed, I had to determine the most appropriate analysis framework for these data. Evidently, it is more challenging to design a suitable analysis once the data have already been collected since data collection cannot be modified to suit the chosen analysis framework. Whereas quantitative analysis primarily addresses questions of fact (see section 4.3.1), qualitative analysis methods primarily address questions of process and reason ('how' and 'why' questions) and offer greater insight into participant experiences (Richardson et al., 2011, Sullivan, 2010).

Qualitative research is built on different philosophical foundations from quantitative research. Adopting a positivistic research philosophy leads a researcher to be sceptical of participant experiences, use objective methods, favour quantitative data, seek strict experimental control and emphasise the importance of replicability (Robson, 2002). Not all philosophers and researchers share the positivist view. Brewer (2000) emphasises the importance of studies approximating real-life situations to have ecological validity. Social constructionists, for example, emphasise the formulation and maintenance of knowledge through social processes (Burr, 2003, Berger and Luckmann, 1966, Barnes, 1974). Adopting a social constructionist research philosophy leads a researcher to examine evidence in terms of whether it is plausible and compelling rather than seek truth, investigate why people hold certain views, often use language-based research methods and value participant accounts (Sullivan, 2010). Moreover, judgements of the transferability of findings outside their original context are left to the reader's judgement (Richardson et al., 2011). It has been argued that constructionism (the related term 'constructivism' is used by some authors) is the only appropriate framework for qualitative

research (Guba and Lincoln, 1989). The compatibility of qualitative and quantitative methods is discussed in section 4.3.4.

I decided that qualitative methods would be the most appropriate to analyse my comment data. They are uniquely suitable to the analysis of textual data, provide an insight into participant experience and emphasise the social perspective. Regardless of whether the data were collected orally or in written form, the data could be considered textual in nature. There were several potential analysis frameworks for data of this nature. These included discourse analysis, conversation analysis, thematic analysis and qualitative content analysis. I shall now outline these in turn and provide a rationale for my decision.

Discourse analysis (Wiggins and Riley, 2010) is a means of assessing discourse, which sees it as representing a particular construction of reality, which in turn has consequences for the speaker's social interactions and self-concept. It seeks to understand how the combination of words into a text or other discourse form projects a view of reality. Discourse can include written, oral and pictorial information. Conversation analysis is a means of assessing a variety of structures within a conversation (Forrester, 2010). These include turn-taking, sequence and emphasis. It seeks to understand how people interact during a conversation.

The above approaches focus on construction of meaning from discourse and interaction during conversations respectively. I decided that they were not suitable for my analysis. I required an analysis framework that instead focuses on extracting key themes from a text or transcript. Therefore, I investigated thematic analysis and qualitative content analysis further, in order to assess their suitability.

Although thematic analysis and qualitative content analysis are both common methods in qualitative healthcare investigations, there has been a lack of definitional clarity regarding the distinction between the methods (Vaismoradi et al., 2013, Sandelowski and Leeman, 2012, Braun and Clarke, 2006). These methods both employ a relatively low degree of interpretative transformation (Sandelowski and Barroso, 2003). The methods have a lot of shared ground, although I shall outline some key differences. For an exhaustive discussion of these two methods, see Vaismoradi et al (2013).

Thematic analysis is a purely qualitative analysis method (Braun and Clarke, 2006). On the other hand, although qualitative content analysis is now widely used, early content analysis was primarily quantitative (Graneheim and Lundman, 2004). Content analysis allows simultaneous quantitative and qualitative analysis (Gbrich, 2007). Content analysis allows analysis of patterns of word use and communication strategies in addition

to extracting themes (Powers and Knapp, 2006). In this regard, it is a more versatile approach.

I decided to use qualitative content analysis (QCA). In addition to performing qualitative analysis of the key themes in the data, it allowed me to quantify how many participants contributed to each theme. This in turn permitted me to assess the most common themes across the sample. I performed an inductive rather than deductive content analysis since there was limited extant knowledge about the phenomenon of study, with the result that it was more appropriate to work from the specific to the general. Analysis procedures were based on a published framework (Elo and Kyngäs, 2008) and are described in detail in section 6.3.1.

4.3.4 Multimethod research

In reality, positivism and relativist theories such as constructionism form a continuum and many researchers' views fall between these endpoints (Sullivan, 2010). Richardson et al (2011) states the importance of choosing the most appropriate methodology for each research investigation. This gives rise to the concept of mixed methods research. Johnson et al (2007) asked leading researchers to define mixed methods research and found that some experts used mixed methods only to refer to mixing quantitative and qualitative methods, whereas other experts included any combination of different methods. My study used mixed methods in the narrower sense, but also mixed different quantitative approaches in a cross-sectional observational design and a within-participants experimental design. I have used the term multimethod research (Hunter and Brewer, 2003) to refer to mixing methods in this broader sense. For the sake of clarity, I shall reserve the term 'mixed methods' for combinations of quantitative and qualitative methods.

Mixed methods research seeks to break down the traditional dichotomy between positivist quantitative and constructionist qualitative research. Campbell and Fiske (1959) provided the first systematic exposition of the benefits of mixing methods. As a result of the different philosophies underlying quantitative and qualitative research, purists in each camp have argued that they are incompatible and should not be mixed (Schrag, 1992, Lincoln and Guba, 1985). However, Johnson and Onwuegbuzie (2004) claim that mixed methods research is a pragmatic and useful third paradigm, whose time has come. They claim that combining quantitative and qualitative methods can magnify the strengths and cancel out the weaknesses of each approach. Mixed methods research is predominantly based upon the philosophy of pragmatism (Tashakkori and Teddlie, 2003). Pragmatism is a philosophy which originated in America in the 1870_s and contends that most

philosophical topics are best viewed in terms of their practical uses. For a review of pragmatism, see Maxcy (2003). Pragmatism would argue that it is important to choose the most appropriate method to assess each research question, rather than a particular researcher having a set method or list of methods that are applied to all research.

Multimethod research has notable advantages. Richardson et al (2011) states that multimethod research can be used in five different ways. Triangulation can achieve convergence by studying one phenomenon using different methods. Complementarity can clarify findings from one method using a different method. Development can use the results of one method to inform another method. Initiation can investigate contradictory results from one method using another. Expansion can use multimethodology to extend the range of enquiry. Johnson and Onwuegbuzie (2004) state that mixing methods can combine the relative strengths of quantitative and qualitative research, provide stronger conclusions through corroboration and address a wider research question.

While a cross-sectional observational design served as the basis of my overall research design (see section 4.3.1), I adopted a multimethod research approach to include a within-participants experimental design and qualitative content analysis. I aimed to choose the most appropriate design to investigate each research question. Embedding a within-participants experimental design into the listener assessment phase of my speech analyses enabled me to optimise student resources and achieve maximal control over assessor variables. Embedding qualitative content analysis into my investigation of the impact of Parkinson's disease on communicative participation provided triangulation to corroborate the results from CPIB using accounts of participant experience. Embedding qualitative content analysis into my CPIB validation study provided a different perspective which demonstrated acceptability of CPIB to participants. Therefore, the use of a multimethod research approach was beneficial to my study.

4.4 Participant recruitment

4.4.1 Identification of suitable recruitment routes

When selecting potential recruitment routes, there were several criteria I had to consider. The potential site had to have a relatively large number of people with PD on its books. A suitable site had to be able to confirm diagnosis to the standard of probable idiopathic PD disease (see section 4.4.2). It was preferable that sites were located as close to Norwich as possible. I recognised that it was advantageous to seek sites that had worked with members of the supervisory team previously. I generated a list of options and discussed these with members of the study management group which I chaired and with

the wider steering committee chaired by Dr Deane. As a result of these discussions, four candidate sites emerged for further consideration.

These were the Neurology and Medicine for the Elderly clinics at the Norfolk and Norwich University Hospital, the Adult Speech and Language Therapy clinic at the Norwich Community Hospital and the charity Parkinson's UK. I decided that Addenbrooke's Hospital in Cambridge, and other hospitals in the eastern region, would only be considered in case of recruitment difficulties, due to the time and cost implications of travel both to the sites and to visit patients attending these clinics. Cambridge, for example, is 66 miles (106 kilometres) from Norwich and the county of Cambridgeshire extends a further 22 miles beyond. I decided that Parkinson's UK would also only be considered as a site in case of recruitment difficulties, since it did not hold sufficiently detailed diagnostic information about members to meet the inclusion criterion of probable idiopathic PD. Dr Deane and I held meetings with the three remaining candidate sites to discuss our requirements and the acceptability of the study to the sites.

Due to staffing issues, I was unable to gain management approval for patient database searches to be conducted at the Norwich Community Hospital. Concerns were also raised about the level of diagnostic specificity held on the clinic records. The alternative offered was a leaflet being available in the clinic. I decided that this would not allow my inclusion criteria to be assessed satisfactorily. Therefore, I withdrew my application for the Norwich Community Hospital to be a site in my study. Following productive meetings, my Research and Development (R&D) application for the Neurology and Medicine for the Elderly Clinics at the Norfolk and Norwich University Hospital (NNUH) to serve as sites was approved. Both sites offered the potential for database searches and held sufficiently detailed diagnostic information for my inclusion criteria to be applied. A particular benefit of recruiting from both clinics was the age range covered, which would increase generalisability of the study results.

4.4.2 Inclusion criteria

I decided to set a lower age limit of 18 for all participants in order to prevent unnecessary ethical complication. Since PD is age-related (Van Den Eeden et al., 2003, Mayeux et al., 1992), I decided it would not be appropriate to impose an upper age limit. The lower age limit was unlikely to exclude any people with idiopathic PD. The absence of people under 18 in the CP group improved group equivalence.

Following discussion with our steering committee movement disorders specialist neurologist Dr Worth, I decided that it was important to seek diagnostic specificity for

idiopathic PD, as opposed to Parkinsonism. This decision was made because of the potential for differential cognitive consequences of Parkinsonism of differing aetiology. I decided to refine this criterion to probable idiopathic PD in order to include people with early PD, since speech impairment can be found in the early stages (see section 2.4.1). The criterion for probable idiopathic PD was set at three of the four aspects of the United Kingdom Parkinson's Disease Society Brain Bank Criteria (Gibb and Lees, 1988). Alternative criteria are available (Calne et al., 1992, Gelb et al., 1999). However, the identification centres routinely used the United Kingdom Parkinson's Disease Society Brain Bank Criteria, which have been widely used in research.

My study investigated the association between cognitive status without dementia and a range of speech and communicative outcomes. Therefore, clinics identified patients with dementia from their records and did not invite these patients into my study. In order to avoid confounding my results, I asked identification centres to exclude patients who had previously had other serious medical conditions which could affect cognitive status or speech, for example a stroke. Clinics were also free to exclude anyone whom they deemed would be inappropriate for the study, for example as a result of personal circumstances.

My study investigated speech and communicative impairments in PD. Therefore, I imposed an inclusion criterion that eligible potential participants should be experiencing difficulties with their speech and/or communication. They should also answer positively to the questions "Do you find that people have more difficulty understanding what you say than they used to?" or "Do you find that people ask you to repeat what you say more often than they used to?"

PwPD were asked to invite a CP (see section 4.4.4) to join them in the study. Except for a minimum age of 18, the only inclusion criteria for CPs were that they did not have PD and had not had serious medical problems affecting either their cognition or speech. It was important that PwPD were as free as possible to choose their preferred CP. It was stated in the protocol that should CPs arrive for the study, who are competent to consent but are not eligible to take part, for example due to a speech impairment, they should be allowed to take part for the benefit of the PwPD and then be subsequently excluded from analyses.

4.4.3 Sample size considerations

There were several practical limitations on the sample size used in this doctoral study. There was a restricted time schedule for recruitment and data collection. This was

to ensure sufficient time to conduct phonetic analysis and listener assessment, and leave sufficient time to write the thesis. There were financial limitations on the number of study visits that could be conducted. There were also human resources limitations, in so far as I conducted all the study visits, performed the speech analyses and some of the statistical analyses, and was responsible for study management and administration. This meant that it was not feasible to conduct phonetic analysis (see section 5.4) on the entire sample. As described in section 5.5, the speaker-to-listener ratio for listener assessment of read sentences is restricted to avoid significant familiarity biases.

In addition to pragmatic factors, I also performed statistical power analyses as part of the process of deciding the target sample size for this study. I defined the relationship between cognitive status as measured by the Montreal Cognitive Assessment (see section 4.6.4) and communicative participation as measured by CPIB (see section 4.6.6) as my primary relationship of investigation, upon which my sample size should be based. Since this relationship was only assessed in PwPD, no target sample size for CPs was set. I deemed it important that PwPD did not feel unable to take part if they could not find a suitable CP. This could also have introduced selection bias into our PD sample. I accepted that the number of CPs in the study would equate to how many of the PwPD were able to identify a suitable CP.

On the advice of my statistical adviser Dr Clark, I used Arsham's (1994) sample size calculator to calculate my target PD sample size based on an expected moderate correlation of around 0.5 between cognitive status and communicative participation. I expected a moderate association due to the complex inter-relationships with other demographic and clinical characteristics. Based on a combination of the output of this calculation and pragmatic factors, it was decided to set a target sample size of 40 PwPD. This would achieve satisfactory statistical power allowing for an exclusion rate of 10% for drop-out and technical failure. As a result of the resource constraints on speech analyses outlined above and discussed in more detail in sections 5.5 and 5.6, I decided to limit the sample size for phonetic analysis and listener assessment to 20 PwPD and 20 CPs.

4.4.4 Recruitment process

Initially invitation of potential participants at the approved sites took place on an ad hoc voluntary basis by clinic staff since my project budget did not include any specific funds for participant identification. However, after a considerable period of slow recruitment, I decided that it was necessary to employ a data clerk to work one day a week. It is important to find local commitment to a research study, rather than solely the requisite management approvals, in order for a study to recruit successfully (Bird et al.,

2011). This review also states that conducting psychosocial studies in a primarily biomedical environment can be challenging. Once the data clerk was in post, the problem of slow recruitment was solved. The data clerk screened the clinic database for patients meeting the inclusion criteria who were scheduled to attend clinic two weeks later. After excluding any patients whom the relevant clinic did not deem it appropriate to invite, the data clerk posted invitation packs to eligible patients. I included a stamped addressed envelope for interested potential participants to send me a reply slip which contained their telephone number. Then I telephoned all interested potential participants to discuss the study, answer any questions and book an appointment if they wished to proceed.

PwPD who expressed interest in participating in the study were invited to ask a friend or relative fulfilling the criteria in 4.4.1 to take part as a CP (see Appendix 4). CPs performed the same speech tasks as PwPD but not did complete questionnaires with the exception of a short demographic questionnaire. This decision was taken following study management group review of the key aims of my study and ethical issues regarding the time commitment of participants.

CPs served a practical purpose in assisting PwPD who had handwriting difficulties in the completion of study questionnaires. Moreover, they served as controls in the speech analyses. This meant that I could ascertain that the speech acoustics, intelligibility and emotional conveyance of PwPD in my study differed from CPs in objectively measurable ways. In turn, this provided assurance that this relatively mild sample did have speech impairment of varying degrees of severity when interpreting the impact of this speech impairment in turn on everyday communication. I decided it was advantageous, where possible, for PwPD to have familiar CPs, in the light of evidence that people with speech impairment modulate their conversational strategies as a function of interlocutor familiarity (King and Gallegos-Santellan, 1999). However, to my knowledge, this effect has not been studied specifically in PD, and it is possible that cognitive impairment, especially with regards to attentional set-shifting, may affect the ability of PwPD to modulate their conversational strategies between familiar and unfamiliar CPs. Holtgraves and McNamara (2010), for example, found impaired ability to modulate conversation as a function of the relative status of the interlocutors and the communicative situation. In the absence of clear evidence on this matter, I decided to seek familiar CPs. When PwPD could not provide a CP or wished to take part alone, I performed the role of the CP. I decided to use conversations with a familiar CP where possible in the speech analyses, subject to sufficient data availability.

4.4.5 Informed consent procedures

The participant information leaflet (Appendices 5 and 6) distributed with the invitation letter (Appendices 7 and 8) provided details of why the study was being conducted and what it would involve. It was made clear that participants could withdraw from the study at any time without prejudice to future care and with no obligation to give the reason for withdrawal. Upon receipt of the reply slip, I telephoned the potential participant. An opportunity to ask me any questions was given before a study appointment was offered. At the start of the study appointment, up to a further half hour was allowed for potential participants to discuss the study with me. Competency was assessed informally throughout the consent process. Training in these procedures was provided by members of the supervisory team before the start of the study.

I asked potential participants to summarise what the study is about in order to ascertain whether they understood the fundamentals of what they would be asked to do and why I was doing the study. I then provided clarification as necessary on the use of video recording, the study questionnaires, the follow-up questionnaire and the intelligibility assessors. I summarised the opportunity to donate audio-visual recordings to a secure controlled-access database for use at conferences, in teaching and for further research. Written informed consent was obtained from all participants by means of a participant and researcher signed and dated consent form.

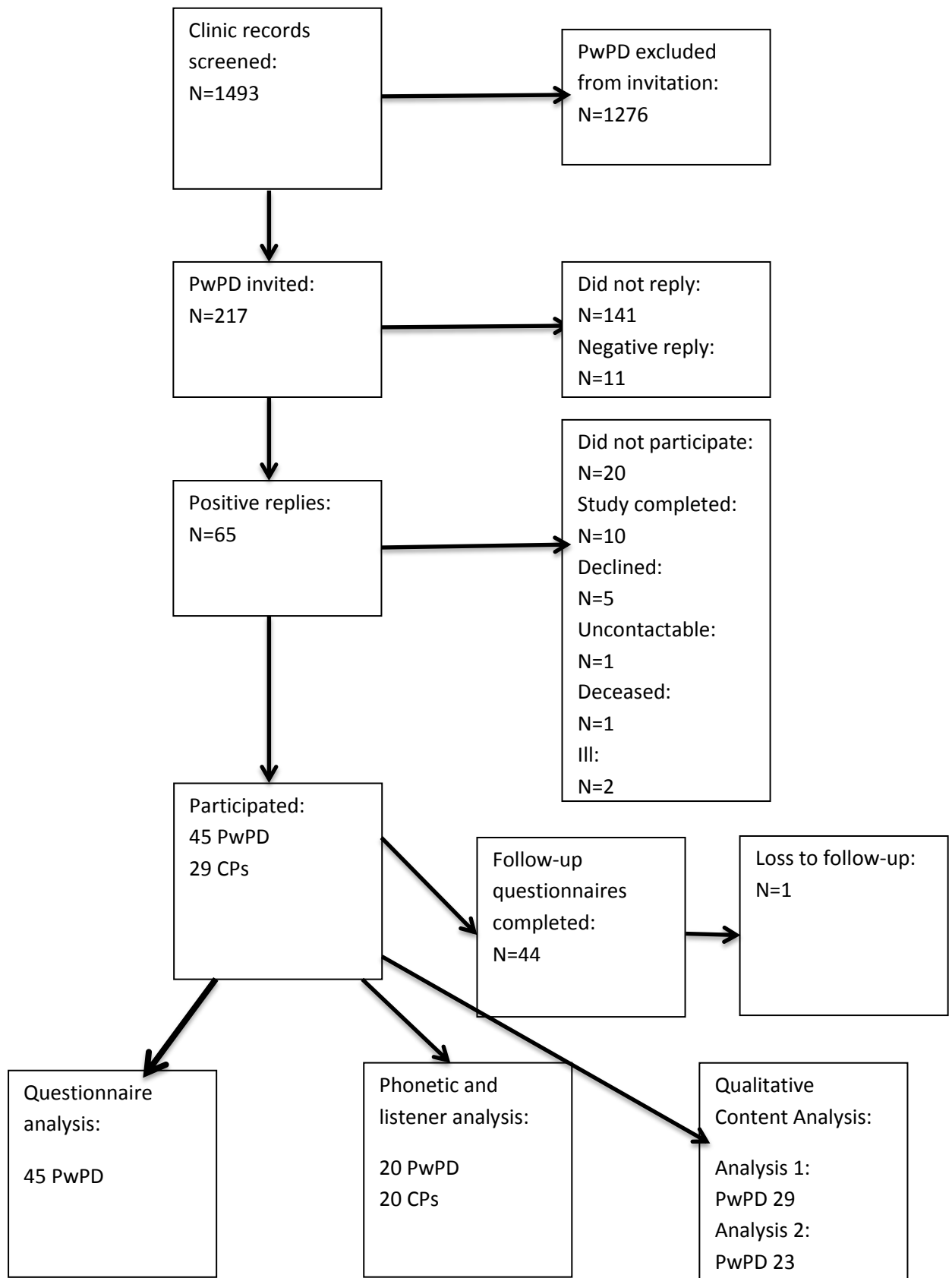
Separate consent forms (see Appendices 9 through 12) were used for the main study and for donating audio-visual recordings to the database. Participants who did not give consent for their recordings to be added to the database were still eligible to participate in the main study. Under the terms of my ethical approval, three original copies were required for consent forms for people with Parkinson's disease (one for the participant, one for the study master file and one for the participant's General Practitioner (GP). Two original copies were required for CP consent forms (one for the participant and one for the study master file). As demonstrated by Milgram's (1974, 1963) studies, the effect of being in a research setting can be persuasive. Therefore, I sought verbal process consent when moving from one study task to the next. Further ethical considerations and approvals are discussed in section 4.7.

4.4.6 Recruitment statistics

One thousand four hundred and ninety-three patient records were screened by clinic staff. Two hundred and seventeen invitations were sent by the clinics. I received 63

replies expressing interest. Forty five PwPD and 29 CPs (see section 4.4.1) participated in my study. More detail is provided in figure 3:

Figure 3: Recruitment flow-chart for people with Parkinson's disease and conversation partners



4.4.7 Demographic and clinical characteristics

Throughout this thesis, mean and standard deviation (SD) are shown as measures of central tendency and variability, with the exception of data which do not fit a Gaussian distribution. In this case median and interquartile range (IQR) are shown instead. The Shapiro-Wilk test (Shapiro and Wilk, 1965) was used in preference to the Kolmogorov-Smirnov test (Kolmogorov, 1933, Smirnov, 1948) to assess normality of distribution, since it has been demonstrated to be the most powerful regularly used normality test when used on a non-Gaussian distribution (Razali and Wah, 2011, Öztuna et al., 2006).

Table 3: Demographic characteristics of people with Parkinson's disease and conversation partners included in this study

		PwPD	CPs
N		45	29
Age		71.00 (8.09)	64.69 (14.71)
Age groups:			
	≤50	1 (2%)	5 (17%)
	51-60	1 (2%)	2 (7%)
	61-70	19 (42%)	10 (35%)
	71-80	19 (42%)	9 (31%)
	81-90	4 (9%)	2 (7%)
	≥90	1 (2%)	1 (3%)
Gender:			
	Male	28 (62%)	8 (28%)
	Female	17 (38%)	21 (72%)
Smoking status:			
	Never	25 (56%)	14 (48%)
	Past	19 (42%)	9 (31%)
	Current	1 (2%)	4 (14%)
	No answer	0 (0%)	2 (7%)
Accent:			
	SSBE	26 (58%)	11 (38%)
	Estuary	3 (7%)	6 (21%)
	East Anglia	8 (18%)	6 (21%)
	Midlands	0 (0%)	1 (3%)
	Northern	5 (11%)	3 (10%)
	Scottish	2 (4%)	1 (3%)
	Welsh/West	1 (2%)	1 (3%)
Education:			
	No formal	17 (38%)	5 (17%)
	GCSE*	5 (11%)	9 (31%)
	A Level*	3 (7%)	1 (4%)
	Vocational	13 (29%)	10 (35%)
	Undergraduate degree	5 (11%)	0 (0%)
	Postgraduate degree	2 (4%)	4 (14%)
Employment:			
	Professional	17 (38%)	11 (38%)
	Administrative management	10 (22%)	5 (17%)
	Technical and practical	9 (20%)	5 (17%)
	Service and administration	8 (18%)	7 (24%)
	Elementary	1 (2%)	1 (3%)

SSBE= Standard Southern British English, *= or equivalent

Table 4: Clinical characteristics of people with Parkinson's disease in this study

N	45
PD duration (years)	6.50 (8.25) ^a
MoCA	22.90 (3.61)
HADS	11.00 (8.50) ^a
LEDD	640.50 (656.50) ^a
Speech severity:	
Male	
Mild	27 (61%)
Moderate	15 (32%)
Severe	3 (7%)
Female	
Mild	39 (88%)
Moderate	3 (6%)
Severe	3 (6%)
All	
Mild	32 (71%)
Moderate	10 (22%)
Severe	3 (7%)

^a=median (IQR) rather than mean (SD)

PwPD and CPs were reasonably well matched for age. A difference of six percentage points in mean age resulted from a higher proportion of participants under 50 in the CP sample. The remainder of the age distribution was closely matched. The majority of PwPD were male, whereas the majority of CPs were female. Around half of participants in each group had never smoked. CPs were more likely to be current smokers than PwPD. Both groups were drawn from a wide range of British accent groups, although PwPD were more likely to speak Southern Standard British English. CPs were more likely to have higher educational qualifications, although this was not reflected in employment category.

PwPD in this study had average disease duration of six and a half years, MoCA score of 23 and HADS score of 11. This suggests that on average, PwPD in my study had mild cognitive impairment but were not depressed. LEDD scores reflected on average mid-stage PD, although the high inter-quartile range shows that a wide variety of disease severities was sampled. Seventy-one per cent of PwPD were classified as having mild speech impairment. This selection bias was greater for female than male participants.

4.4.8 Evaluation of recruitment

Target numbers were reached. PwPD in my study originated from a wide range of locations in the UK. This increases the generalisability of my speech findings. A wide range of overall PD was found. However, there was a selection bias towards people with more mild speech impairment. I believe this results from self-consciousness of many people with more severe speech impairment about their speech and especially being recorded. The gender balance differed markedly between PwPD and CPs. This is because PD is more prevalent in men (Van Den Eeden et al., 2003, Mayeux et al., 1992) and the majority of CPs were opposite gender life partners. However, gender was taken into account in analyses where appropriate.

4.5 Designing the data collection session

In designing and conducting the study it was important to make as many reasonable adjustments as possible for participant disability. A small proportion of PwPD were unable to communicate on the telephone. Anticipating this situation, I allowed a carer to discuss the study with me and make the appointment. When I arrived for the study appointment, I then had the opportunity to discuss the study again with both the patient and the carer in a more suitable environment and answer any questions.

Travel is a major barrier for many PwPD. Therefore, it was essential for me to design a portable data collection session that I could bring to people's homes, in order to maximise recruitment. The technical challenges and my solutions regarding speech recordings are described in section 5.4. My budgetary calculations revealed that visiting the majority of people in their own home would allow the geographical boundaries to be extended from Norfolk to patients living in neighbouring counties but attending the NNUH. This is because I did not have to take into account potential long-distance taxi fares for participants from outlying areas to reach the university. Norfolk is a county in which a considerable proportion of older people live in outlying towns and villages with limited public transport connections to Norwich. PD is also associated with impaired driving (Meindorfner et al., 2005, Heikkilä et al., 1998).

In order to be maximally convenient to my participants, I also offered the option of coming to the UEA. Of my 45 participants, three selected this option. The majority of my participants said that they would not have taken part if a visit to UEA had been required. There were challenges in finding a suitable location for appointments at the university. The selected location should be quiet, confidential and have disabled parking facilities

nearby. I arranged to use a meeting room in the School of Nursing Sciences, which has a car park and a lift to all floors. Although this was the best location available at the time for the few appointments that took place on campus, it was not ideal. The building has few meeting rooms away from the main stairwell area. This means that they are not always ideally quiet for recording purposes. On one occasion, during university term, it was necessary to vary the order of tasks to find suitably quiet times to make recordings.

Only on one occasion did I experience significant difficulties with data collection in the field, when I had to exclude speech recordings from a participant who lived on a major road, due to the road noise interfering with the quality of the speech recording. In comparison, during two of my three study sessions conducted at the university, it was necessary to alter the task order due to temporary noise issues. My experiences show that collecting data in participants' homes where possible is far more convenient for participants in PD studies, leads to higher recruitment rates and does not have a detrimental effect on data quality. Indeed, Ladefoged (1997) presents certain advantages of recording in the field. Recording considerations are discussed in section 5.3.

Fatigue is common in PD (Karlsen et al., 1999). Therefore, it was essential for me to design a data collection session which was both thorough and concise. It was important to use brief assessments where possible (see section 4.6 for details). Participants varied considerably in how long they took to complete the session, ranging from thirty minutes to an hour and a quarter, after consent had been obtained. However, the session was designed so as to be able to be completed by the vast majority of participants in under an hour after consent. If participants were experiencing fatigue, breaks were offered between tasks. I designed the study with the speech tasks first and alternating between the patient and the carer, in order to minimise the effect of fatigue on speech. However, on occasion it was necessary to vary the task order due to late arrival or unavoidable early departure of the CP or temporary noise problems which prevented speech recordings being made at that time.

A significant minority of PwPD experienced severe tremor-induced handwriting difficulties. Questionnaires were designed to be tick-box as much as possible. The demographic questionnaire required more writing, so was administered orally with the majority of PwPD. In cases when the participant was unable to complete tick-box questionnaires using handwriting, either the CP or I asked the questions orally and marked the responses on behalf of the PwPD. I had to take care to ensure that CPs only marked answers on behalf of people with Parkinson's disease and did not generate answers on their behalf. A small number of PwPD had difficulty completing the consent forms, especially as they had to be completed in triplicate and required initials to be

written in the boxes rather than merely making a mark. All participants were able to sign their name with assistance.

Due to handwriting fatigue following a series of questionnaires, the majority of participants wanted to answer the post-CPIB feedback task in oral rather than written form. I checked with all participants that they were happy to continue. In cases where participants were too tired after the other assessments or did not wish to continue for any reason, I did not ask these questions. As a reasonable adjustment for participant disability, I therefore conducted the post-CPIB feedback task in oral form for participants who requested this. I started by asking a prompt question about the acceptability of CPIB to participants. This was based on the intended written form question: 'This scale has been developed in the USA. We would appreciate if you could tell us whether there were any difficulties with the language which affected understanding. If so which questions were particularly difficult to understand?'. Participants discussed their views on CPIB with me. Then some participants wanted to explore some of the wider issues of speech and communication in PD that were implied in the initial prompt question. The discussion was free-form and its direction determined by what participants wished to discuss. Although many participants explored aspects of speech and communication in general beyond the original prompt question, the discussion did follow from this prompt and I decided it would be unethical to cut participants off when they wanted to discuss these wider aspects with me. The scope and content of responses did not differ substantially between those provided in oral and written form.

In order to assess the test-retest reliability of the CPIB in my population (see sections 4.6.6 and 6.2), I re-administered this scale by post two weeks after the data collection session. I provided a stamped addressed envelope. I chose a follow-up period of two weeks because I believed it to be sufficiently long that participants would not recall their original answers, but not long enough for participants to have forgotten about the study or for the study to incur a high attrition rate for other reasons.

4.6 Assessments

The data collection session comprised baseline demographics, speech recordings (see sections 5.2 and 5.3), and assessments of cognitive status, anxiety and depression, and communicative ability and participation.

4.6.1 Demographics

I compiled a demographic case report form based on characteristics that I believed could be confounding variables in the topic of interest. I then transformed this into questionnaire form to be an accessible self-report measure for participants (see Appendices 13 and 14). Age, gender and smoking status can affect the physiological substrates of speech and therefore were included on the demographics questionnaire. Age and gender can also impact on speech, language and communication at a socio-cultural level. Since age and smoking status were relatively similar between PwPD and CPs in the purposive sample (see section 5.4.2), they were not entered as covariates in the speech analyses to increase statistical power. Since gender differed significantly between PwPD and CPs (see section 5.4.2), it was frequently included as a covariate in speech analyses.

Another important socio-cultural factor in studies of speech and communication is accent. Only three to five per cent of people in England have a totally regionless accent and no more than twelve to fifteen per cent can be defined as native speakers of 'standard English' (Trudgill, 1999). Using Trudgill's terminology, I define accent as how people pronounce English. It differs from dialect which involves the use of 'non-standard' words and grammar. Different accents of the same language can vary significantly in terms of pronunciation and consequent acoustic characteristics (Trudgill, 1999, Clopper et al., 2005, Labov, 2006, Yan and Vaseghi, 2003) and this can affect automated recognition (Yan and Vaseghi, 2002), although under normal circumstances human perception can usually adjust (Evans and Iverson, 2004), especially in younger listeners (Adank and Janse, 2010). There is mixed evidence as to whether native speakers' comprehension in good listening conditions is significantly affected by regional accents of their own language (Major et al., 2005, Adank and McQueen, 2007). Intelligibility of unfamiliar accents can however be reduced in sub-optimal listening conditions (Munro, 1998).

Although accent is fundamentally a multi-dimensional continuum, for practical reasons it was necessary to categorise it into a relatively small number of accent groups for the purpose of this study. Based on the accent profile of participants recruited into this study, I categorised accent broadly on pragmatic grounds into Standard Southern British English (SSBE), Estuary English, East Anglian, Wales and West, Midlands, Northern and Scottish. For more information on regional British accents, consult Hughes et al (2012) or Wakelin (1985). A wide variety of accents was an advantage for generalisability. However, it was important to ensure the Parkinson's disease and CP partner groups were

adequately balanced for accent in phonetic analysis and listener assessment (see section 5.4.2). Due to low numbers in each accent group, I did not include accent as a covariate in speech analyses, once I had ensured that groups were sufficiently balanced for accent.

For educational status and employment category, I had to devise suitable categorisation structures. I decided to classify education in terms of highest education qualification obtained rather than number of years of formal education, because I believed the former to be a more sensitive measure of educational attainment as opposed to attendance. I used a six point system based on the six generally accepted categories of educational qualification available from the age of 16 in the UK. I asked participants to select the highest point on the scale at which they held a qualification. Although only British qualifications are discussed here, since none of my participants held educational qualifications from other countries, the principles of the categorisation are readily transferable. Scottish and historical UK qualifications are mentioned since they were taken by some of my participants. Many of these qualifications are more commonly known by abbreviations, which are shown in brackets.

The first category was the absence of formal educational qualifications.

The second category was General Certificate of Secondary Education (GCSE) or equivalent school examinations taken at the age of 16. Equivalent current qualifications include Scottish Standard Grade. Ordinary Levels (O-Levels) (1952-1988) and the School Certificate (1918-1951) were also considered equivalent for the purposes of this classification.

The third category was Advanced Level (A-Level) or equivalent school examinations taken at the age of 18. Equivalent qualifications include Scottish Advanced Highers or their precursor Certificate of Sixth Year Studies (CSYS). Due to differences in the relative durations of secondary and higher education in Scotland, a Scottish Higher which is technically an equivalent of an English Advanced Subsidiary Level (AS-Level), which is taken a year earlier than A-Levels, was also considered as an equivalent qualification for the purposes of this study.

The fourth category was vocational qualifications. This category included any professional or trade-related qualifications that were awarded at a level lower than a degree, for example certificates and diplomas. These could include Postgraduate Certificate of Education (PGCE), City and Guilds, Business and Technology Education Council (BTEC) qualifications and their historical equivalents.

The fifth category was an undergraduate degree. This category included Bachelor of Arts (BA), Bachelor of Science (BSc), Bachelor of Engineering (BEng) and Bachelor of Education (BEd) degrees.

The sixth category was a postgraduate degree. This category included Master of Arts (MA), MSc, Master of Engineering (MEng) and Master of Education (MEd) degrees, as well as all academic, clinical and professional doctorates. Postgraduate qualifications awarded at a level lower than a degree, for example in education or accountancy, were assigned to category four.

Regarding employment category, the study sample size was insufficient to use the International Standard Classification of Occupation (International Standards Organization, 2008). It has ten categories and is designed for very large samples, for example from the census. When I investigated its potential use in my sample, I found that many participants could equally be assigned to several categories and that the numbers in each category were too low for statistical analysis. Therefore, I devised a broader five-point categorisation which was sufficient for the purposes of my study. It draws upon aspects of the International Standard Classification of Occupations, the National Standards Socio-economic Classification (Office for National Statistics, 2010) and the Social Class based on Occupation (Office of Population Censuses and Surveys, 1990) systems.

The first category included professionals and senior professional managers. The second category included junior and administrative managers as well as foremen, supervisors and managers in practical trades. The third category included all non-managerial workers in practical and technical trades. This category included for example hauliers, plumbers, chefs, IT repair technicians and skilled construction workers. However, software developers and graduate engineers were classed as professionals rather than technical workers. The fourth category included non-managerial administrative staff, including personal assistants and secretaries. The fifth category was elementary occupations, which included cleaners, kitchen porters and unskilled labouring occupations.

4.6.2 Medication

Due to evidence that medication may affect cognition (see section 2.3.5) and speech (see section 2.4.5), it was important to quantify the medication taken by Parkinson's participants and include it where appropriate as a covariate in analyses. A wide range of medications are prescribed for PD, often in poly-pharmacy, covering different drug classes. These include levodopa-based medications, dopamine agonists

and monoamine oxidase B (MAOB) inhibitors. Therefore, it was important for me to use a quantitative measure to provide a measure of medication load expressed in terms of levodopa dose equivalents. I used the Levodopa Equivalent Daily Dose (LEDD) formula (Tomlinson et al., 2010), which resulted from a systematic review of levodopa equivalency dose reporting.

4.6.3 Severity of speech impairment

For phonetic analysis and listener assessment, it was important to ensure an optimal balance of speech severity and severity by gender profiles in the PD sample (see section 5.4.2). As a linguist and phonetician, I assessed speech severity perceptually using read, mood and conversational speech recordings. Categorisation was based on a perceptual assessment of the speech features addressed by the measures in section 5.4.4.1: namely intensity, pitch, rate, fluency, voice quality and articulatory precision. This speech severity categorisation was only used for purposive sampling in preparation for phonetic and listener analyses and not as an outcome measure. Therefore, the results of these objective analyses were not available to inform this severity categorisation. I wanted to provide an overall categorisation of the severity of speech impairment to inform my purposive sampling for acoustic and listener analyses. Therefore, it would not have been appropriate to use scales such as the Consensus Auditory-Perceptual Evaluation of Voice (Kempster et al., 2009) and GRBAS (De Bodt et al., 1997), which focus exclusively on voice quality.

4.6.4 Cognitive status

As detailed in section 2.3, cognitive impairment short of dementia is relatively common in PD. This is often called mild cognitive impairment. I started my study prior to the publication of the new MDS criteria for mild cognitive impairment (see section 2.3.1.1). The principal relationship of interest in my study was between cognitive status and communicative participation. All other investigations and associations were secondary matters of interest. For this principal relationship, I wanted to use a continuous measure of cognitive status in order to capture the effect of a range of levels of cognitive status, in the range of normal cognition and mild cognitive impairment, on communicative participation. This gave a more detailed picture of this primary relationship than would be provided by a bi-partite split at a mild cognitive impairment criterion. Therefore, I did not seek to define mild cognitive impairment in my sample.

In order to provide the intended detailed investigation of this primary relationship between cognitive status and communicative participation, it was essential to use a

sensitive instrument. Although it would have been ideal to use a brief instrument which has been validated in PD in the UK, no such assessment could be found. It was important that the assessment was brief due to the range of assessments being administered in one session. Therefore, I considered brief instruments that had been validated in PD in an English-speaking country.

The MMSE (Folstein et al., 1975), which until recently was almost a *de facto* choice as a brief cognitive assessment in research, has been repeatedly demonstrated to be insensitive to mild cognitive impairment in PD (Hoops et al., 2009, Mamikonyan et al., 2009, Gill et al., 2008, Zadikoff et al., 2008, Dalrymple-Alford et al., 2010) relative, for example, to the Montreal Cognitive Assessment (MoCA) (Nasreddine et al., 2005). MoCA is a sensitive brief assessment that can be completed on average in around ten minutes. MoCA has been recommended for use in clinical trials of PD (Chou et al., 2010) in which cognitive impairment is not the primary outcome measure, in which case a comprehensive neuropsychological battery would be used. Therefore, I decided to use MoCA (see Appendix 15) as a suitable brief cognitive assessment in my study. I obtained permission for its use in this study.

4.6.5 Depression

As seen in sections 2.3.4 and 2.4.4, depression may affect cognitive status and communication. Therefore, I wanted to include a brief depression assessment in my study that could be included as a covariate in communication analyses. The selected assessment would ideally include anxiety as well since this is known to be common in PD (Stein et al., 1990, Richard et al., 1996). However, in the interests of keeping the data collection session length manageable, it was decided that separate depression and anxiety assessments would not be used.

MDS task force systematic reviews evaluated depression (Schrage et al., 2007) and anxiety (Leentjens et al., 2008) scales in PD. The Hospital Anxiety and Depression Scale (HADS) (Zigmond and Snaith, 1983) was the only self-report anxiety instrument validated in PD. Three self-report depression measures have been validated in PD. The Geriatric Depression Scale (Yesavage and Sheikh, 1986) has not been adequately evaluated in younger PwPD. The Zung Self-Rating Depression Scale (Zung et al., 1965) contains a large amount of somatic items which overlap with PD symptoms and uses reverse coding which increases cognitive complexity. HADS has little overlap with other PD symptoms, although reverse coding is used. HADS has been shown to have good test-retest reliability and internal consistency in PD (Marinus et al., 2002). However, limited psychometric validity data are available and face validity is moderate (Schrage et

al., 2007, Leentjens et al., 2008). I decided to use HADS (see Appendix 16) since it includes anxiety and depression, has satisfactory reliability and has limited overlap with other symptoms of PD. Licensed scale copies were obtained.

4.6.6 Communicative activity and participation

I wanted to assess the effect of cognitive status on both communicative effectiveness (ICF Activity level) and communicative participation (ICF Participation level). I performed an initial search for a measure of communicative effectiveness and a measure of communicative participation which had been validated in the UK in PD. However, no such measure could be identified for either outcome. Therefore, I expanded my search to include measures that had been validated in PD in an English-speaking country. While recognising that relatively few measures exist in this field and no gold standard exists, I sought one activity measure and one participation measure, with as little overlap between the measures as possible. In addition, in order to validate my chosen participation scale in the UK (see section 6.2), I sought to identify a second participation scale that had been validated in PD in an English-speaking country.

As a revised search strategy, I initially considered all scales included in Eadie et al.'s (2006) systematic review of self-report measures of communicative participation. I performed subsequent bibliographic searches to include more recently published scales and to expand the search to include activity level measures more explicitly. These combined strategies yielded nine assessment scales for consideration. These were American Speech-Language-Hearing Association Quality of Communication Life (Paul et al., 2004), Burden of Stroke Scale (Doyle et al., 2003), Communicative Effectiveness Survey (Donovan, 2005), Communicative Participation Item Bank (Yorkston et al., 2008, Baylor et al., 2013b), Living with Neurologically Based Speech Difficulties (Hartelius et al., 2008), Voice Activity and Participation Profile (Ma and Yiu, 2001), Voice Handicap Index (Jacobson et al., 1997), Voice-Related Quality of Life (Hogikyan and Sethuraman, 1999) and Voice Symptom Scale (Deary et al., 2003).

I applied two selection criteria. The assessment scale must have been validated in PD in an English-speaking country. It must also focus predominantly on either communicative effectiveness (ICF activity level) or communicative participation (ICF participation level). I considered overlap between activity and participation levels as undesirable, but less serious than overlap with the ICF impairment level.

After applying these criteria, two scales remained for consideration. These were the Communicative Effectiveness Survey (CES) and CPIB. The former is an activity

measure and the latter a participation measure. I decided they were both suitable for my study. The scales are discussed below. Since only one suitable communicative participation scale was identified, it was necessary to use the activity measure to validate the participation measure (see section 6.2).

CES (see Appendix 17) is a brief self-report measure of communicative effectiveness which was developed by Donovan (2005). Donovan et al (2005, 2008) found that PwPD and dysarthria had significantly less effective communication than controls. PwPD reported their own communication to be more effective than reported by relatives (Donovan, 2005, Donovan et al., 2008). Participants were asked for their feedback on the CES. Participants appreciated the brevity of the scale and said that it covered most of their daily communicative activities (Donovan, 2005, Donovan et al., 2008). However, no clearly defined analysis framework for these qualitative data is provided. Satisfactory item-level psychometric properties were found using item response theory Rasch analysis (Donovan et al., 2007).

CPIB is a self-report measure of communicative participation that was developed by the research group that authored the review of communicative participation scales (Eadie et al., 2006), which concluded that there was no suitable extant measure of communicative participation. Initial investigations of CPIB were conducted in spasmodic dysphonia, which is a chronic voice disorder (American Speech Language Hearing Association, Undated). Candidate items were first assessed for suitability and refined in a cognitive interviewing study (Yorkston et al., 2008). Initial item response theory (Baylor et al., 2011, Fayers, 2004) psychometric analyses of 141 candidate items were reported by Baylor et al (2009). Two hundred and eight people with spasmodic dysphonia participated, of whom four were Canadian or British and the remainder American. High reliability was found using Cronbach's alpha. A moderate ($r_s = -0.678$) correlation with Voice Handicap Index scores was found. Since no other extant measure assesses communicative participation, it is to be expected that concordance with other speech and communication measures will be moderate. Results from the psychometric analyses identified redundant items which could be removed.

Further development work has reduced the number of items. In 2010, an American-based investigation of the CPIB in Parkinson's disease started (C. Baylor, personal communication, 2010). It sought to investigate the suitability of the scale in this population and to reduce the number of items from 94. Following discussions between our research group at UEA and Dr Baylor's research group at the University of Washington, it was agreed that I could use CPIB in my research project. It was agreed

that I would validate the scale in a UK Parkinson's population (see section 6.2), to the extent permitted by the time and resource constraints of my project.

A 46-item interim version of CPIB was supplied for use in my study. At the time when it was necessary for my study to start recruiting, no shorter version of the scale was available. Before my statistical analysis had been conducted, a ten-item disorder-generic short form became available (C. Baylor, personal communication, 2012)(Baylor et al., 2013b). Therefore, I re-scored my completed questionnaires using the short-form mark scheme. Relationships between scores on the short and long forms of the scale are presented in section 6.5.1. CPIB (see Appendix 18) has now been validated in large samples of PwPD in the United States and New Zealand using item response theory methods (Baylor et al., 2013a). There was a minor typographical error in the production of the local copy of CPIB. Question three should have read 'asking questions in a conversation' rather than 'answering questions in a conversation'. This is very unlikely to impact upon any of the results of my study.

4.7 Copyright considerations

Under section 32 of current UK Copyright Law, work presented for examination purposes is exempt from copyright restrictions. Therefore, all published assessments can be included in the examination copy and the hard copy deposited in the school of study. However, subsection five states that the examination exemption does not extend to e-thesis repository deposition. Therefore, I sought permission to include all assessments in the e-thesis. I would like to thank all those who granted permission to include their assessments in the appendix of the e-thesis.

In cases when rights holders would not grant permission for material to be included in this non-commercial educational work or could not be contacted, I could only include a copy of the assessment in the examination copy of the thesis, except as provided for under fair use provisions of UK Copyright Law. A link to the publisher's website or a reference to published materials will be provided in the deposited thesis. The use in this thesis of short illustrative quotations from published works falls under the fair use for review and criticism exemption of relevant UK Copyright Law. Therefore, these quotations will be able to be included in the deposited copy of the thesis.

4.8 Ethical considerations

4.8.1 Participant identification

In order to comply with the NHS Confidentiality Code of Practice, it was necessary to design the identification and recruitment procedures so that no patient identifiable data would be handled by members of the research team without prior patient consent. Therefore, I prepared a site box for each clinic containing invitation packs, stamps and instructions. I explained the identification procedure to clinic staff and left the boxes in clinic. Patient database searching, selection of potential participants and sending of packs was conducted in clinic without the presence of a member of the research team.

4.8.2 Vulnerable adults

This study investigated a potentially vulnerable adult population. Since the study was non-interventional and only recruited adults who were capable to consent, no additional approvals were required besides the standard ethics and governance (see section 4.8.8). However, I completed safeguarding training at UEA prior to starting recruitment. The study management group agreed a procedure, whereby I should notify Dr Deane if I became aware of any potential safeguarding issues. Dr Deane would then assess the incident and decide whether it was necessary to report it to the county council.

4.8.3 Lone worker protocol

UEA has a lone worker protocol. This covers situations in which a member of the university is going off site alone to hold a meeting in a private location with people who are not representing an organization such as a university, business or health authority. Since I visited PwPD and CPs in their own homes, this fell under the remit of the lone worker protocol. This means that I had to contact someone at base upon arrival and departure from the study location. A challenge in nominating the contact person was that, according to the terms of my ethical approval, only named investigators could access names, addresses and telephone numbers of participants. Therefore, this role had to be shared between Drs Deane and Horton.

4.8.4 Depression

The National Institute for Clinical Excellence provides guidance covering the use of depression assessments in research settings. It recommends that if possible depression is indicated, the researcher should give the participant a leaflet providing

information about depression and how to seek help. Additionally, the Principal Investigator should notify the participant's General Practitioner (GP) in writing. I explained this procedure to all participants before seeking consent for the study. I used a different leaflet for mild depression and moderate-to-severe depression (see Appendices 19 through 21) in order to provide more appropriately tailored advice.

4.8.5 Video recording

I decided that it was essential to make audio-visual as opposed to purely audio recordings of participants' speech and to retain facial detail in these videos. In this study I aimed to design speech tasks that were as naturalistic as possible, in an attempt to move away from 'laboratory' speech tasks that have prevailed in previous research (see section 2.4) towards an approximation of everyday life. Everyday communication is predominantly audio-visual in nature. Additionally, a small study by Miller (2008a) suggested that the presence of audio and visual cues reduced the emotional conveyance of PwPD as a result of temporal conflict between the modalities. I wanted to investigate this suggestion further. Therefore, it was important for audio and visual cues both to be available in listener assessment (see section 5.5).

However, the use of video recording poses particular ethical challenges. According to UK Data Protection Law, video data are considered personal data. It is evident that the possibility of a person being recognised from a video recording is much greater than from an audio recording alone. No extra ethical approvals were required for the use of video recording, but I had to demonstrate to the ethics committee that its use was necessary and that suitable data storage provisions were made (see section 4.8.6). When taking informed consent for participation (see section 4.4.5), I had to ensure that potential participants fully understood how their video recordings would be stored and used in the study analyses, as well as which suggested uses of the video were optional (see section 4.8.5). Potential participants could take part in the study without agreeing to these extra uses of video recordings.

4.8.6 Data storage

Satisfactory data storage is important to safeguard the confidentiality of participants and to respect their time and effort by reducing the risk of data loss. An important stage of data storage is the transfer of data from off-site study locations to the university at the end of each study visit. All questionnaires were stored in a folder in my briefcase prior to leaving the study location and put into the boot of my car for transit back to the university. Before leaving the study location, I transferred all video data from the

camera SD card to a specially encrypted sector of my laptop's hard drive. I deleted the recordings from the camera once I had tested the videos on the laptop and ensured that file transfer had been successful. The laptop and all recording equipment were transferred back to the university in the boot of my car. Upon return to the university I transferred the questionnaires to the study master file. I also transferred the video recordings from the laptop to two encrypted external hard drives. I deleted the recordings from the laptop once I had tested the videos on the external hard drive and ensured that file transfer had been successful. The study master file and external hard drives were stored in a locked filing cabinet in a locked room at the university.

While the use of external hard drives for long-term video storage gained full ethics and governance approval, this was not my preferred option. Following a consultation with a data security expert, I decided that network storage would be the best option. It is frequently backed-up, easy to access with the correct credentials irrespective of location and is not stored in a physical location accessible to other people, with the exception of a few specialist technicians. On the other hand, external hard drives are not automatically backed up, can malfunction, need to be manually transported to the location of use and are not stored in a private room. However, the quotation I received for the required network storage exceeded my project budget.

Therefore, despite the limitations outlined above, I had to use external hard drives. To mitigate the risk of malfunction and the absence of back-up, I created two duplicate external hard drives of video files. I also sought expert advice from Mike Stevens formerly of the School of Rehabilitation Sciences (at the time called the School of Allied Health Professions) regarding the best external hard drives to use. On the basis of his recommendation, I chose Western Digital (Western Digital Corporation, Irvine, California) My Passport hard drives. When the drives were not in use, I always stored them in encrypted form in a locked filing cabinet in a locked room at the university.

4.8.7 Archiving

Study data will be archived for five years from study completion subject to any change in university requirements as per the terms of my ethical approval. Dr Deane will retain the study master files and video drives. After five years, that is to say in January 2019, the study data will be destroyed as per university procedures at the time.

However, in recognition of the effort made by participants to take part in my study, I offered them the opportunity to donate their speech recordings to a secure audio-visual database for responsible authorised use in teaching and research. A separate consent

form was used for the database. Database archiving was optional and was not a prerequisite for participation in the study. While I was most willing to contribute my data to the database project and fully support its value, it falls outside the scope of my doctorate and I do not manage the database project.

4.8.8 Dissemination

I recognise the responsibilities and challenges researchers face in disseminating their findings to a wide variety of audiences. Most non-commercially funded research is funded either directly or indirectly by the taxpayer. Additionally participants in health research studies often, as was the case in my study, donate their time freely in the hope of contributing to improvements in future treatment for a condition that affects their life.

The public have a right to see what their money and time is achieving. A major barrier to this until recently has been the predominance of a subscription-based model for journal article access, which has limited access to key research findings to a select group, predominantly consisting of academics, students, healthcare professionals and government bodies. I welcome the recent move by research councils towards mandating open access publication of their research, either through the 'gold' open access journal route or the 'green' institutional repository route. However, there are many challenges still to be overcome including publisher restrictions on the 'green' route. I aim to publish my key results paper using the 'gold' open access model if possible and where possible will archive all of my publications on 'green' open access repositories.

However, open access to research publications is not sufficient to allow the public access to the research they are funding. Academic publications are written in a style that is not accessible to the majority of non-specialists. Therefore, it is an essential ethical consideration that academics also publish their findings in a form which is accessible to the public. I have sent a summary of my findings to all my participants. I was invited to give a talk for the Norwich and District branch of Parkinson's UK. A significant number of my participants were in attendance and this talk gave the opportunity for people from a wide range of backgrounds to ask me questions about the research. I presented a poster at the Fifty Years of the University of East Anglia Postgraduate Research Showcase at the Forum in Norwich, which aimed to present research findings in a format suitable for a public audience in a venue which would be considered home territory for the public.

A major barrier to public engagement in research is asking the public to come to the university, which to many will be unfamiliar territory. I intend to pursue further avenues to make my findings available and accessible to a public audience, as well as to

academic and professional audiences. For example, for each journal article arising from of this study, I intend to write articles for relevant support group and professional magazines.

4.8.8 Approvals

Ethical approval (see Appendix 22) to conduct this study was granted by the National Research Ethics Service Committee East of England-Norfolk. R&D approval (see Appendix 23) for the Neurology and Medicine for the Elderly Clinics at the NNUH to serve as participant identification centres for this study was granted by the Norfolk and Norwich University Hospitals NHS Foundation Trust. Local management approval for the UEA to serve as a non-NHS site in the study was granted. The Dean of Students Office at UEA stated that their approval was not required for any activities to be undertaken in this study. The Chair of the Faculty of Medicine and Health Sciences Research Ethics Committee at UEA said that approval from this committee was not required for the study, since NHS ethical review was being sought, and that the UEA committee did not need to see any of my study documentation.

4.8.9 Amendments

All required protocol amendments were approved by the UEA sponsor's representative, National Research Ethics Service Committee East of England- Norfolk and Norfolk and Norwich University Hospitals NHS Foundation Trust. Amendment approvals and the revised protocol are included in Appendices 25 through 27. Additionally, I notified two matters to the research ethics committee that were not considered substantial amendments.

4.8.10 Protocol breach

4.8.10.1 Summary of events

During the study period, a protocol breach occurred, resulting in a temporary halt to study recruitment. This protocol breach happened when another PhD student at UEA provided me with the names and contact details of study participants from his trial, which had almost identical inclusion criteria. The information below provides further detail.

Dr Deane (secondary supervisor to the other PhD student and my primary supervisor) asked the other student to identify patients suitable for my project from his study database. These are the patients who replied to his study invitation, indicated their

interest and returned the screening questionnaire but were subsequently ineligible for his study.

Retrospective identifying of potential participants was allowed within my study protocol, where it was intended that clinic staff would identify potentially eligible patients (both retrospectively and prospectively) and send them an invitation pack by post from the clinic.

The error occurred when names and addresses of potentially eligible patients were transferred from the other PhD student to me. I received the names and addresses of 90 patients (with the implicit information that they had PD). I then sent invitation packs to 44 of the patients inviting them to participate in their research. This activity breached both study protocols.

I was incorrectly advised by Dr Deane beforehand that this process was acceptable. However, we realised that in fact the invitation letters should have been sent directly by the clinical team and that I should not have had the information that these people had Parkinson's disease, until they had responded to express interest in participating in my research study. This error was recognised by the research teams within a few days of the letters being posted. Both studies ceased recruitment on 10.02.12.

4.8.10.2 Actions taken to rectify

Initially, advice was sought from NNUH and UEA Data Protection Officers regarding whether the Information Commissioner's Office needed to be informed. The Caldicott Guardian was also informed via NNUH R&D in addition to UEA R&D and the sponsor's representative (Sue Steel, Contracts Manager, UEA). The following actions took place:

The Research Governance offices of both UEA and NNUH (having taken advice from the Data Protection Officers for UEA and NNUH) wrote a joint letter (see Appendix 30) to all 90 patients whose data had been inappropriately shared. No patients in receipt of this letter registered a complaint. The NNUH Research Governance Committee met and recommended that those involved complete further training in ICH GCP and NHS Information Governance. This was undertaken by all relevant research team members.

4.8.10.3 Protocol breach conclusion

NRES Committee East of England- Norfolk (see Appendix 31) and the NNUH Research Governance Committee stated that they would be happy for recruitment to restart for both studies once certificates had been received. A letter was subsequently issued on the 27th April 2012 from NNUH R&D office stating that study recruitment was able to resume (see Appendix 32). The restarted recruitment was conducted with the assistance of a nurse specialist within the clinical teams who henceforth identified and sent letters to all potential participants, therefore absolutely preventing recurrence of this error.

4.8.11 Study management

I served as Chief and Principal Investigator for the study. The study management was overseen by two committees. I chaired the study management group which consisted of the three academic supervisors and me. Members of this committee met every month to review progress. The full committee met quarterly. Dr Deane chaired the steering committee which included local clinicians, lay representatives and my statistical adviser Dr Clark. Due to diary commitments, this committee met en masse less frequently than intended. However, it was convened at important stages of the project. I also had more frequent contact with members of the committee as required throughout the study. For example, our lay representatives reviewed the participant information sheets and gave their feedback on CPIB. I also met on several occasions with Dr Clark to discuss the project statistics. No Adverse Events or Serious Adverse Events occurred in the conduct of this study.

4.9 Summary

This chapter initially outlined and provided rationale for my research questions. It then provided justification for combining cross-sectional observational, mixed factorial experimental and qualitative methodologies in this study. It proceeded to present each principal data collection method and assessment in turn, discussing the options and justifying their use. It concluded by addressing key ethical considerations in the study design. The following chapter contains a detailed account of the speech analyses performed in the study and presents the results of these analyses.

Chapter 5: Relationships between cognitive status, speech acoustics, intelligibility and emotional conveyance in Parkinson's disease

5.1 Signposting

This chapter initially outlines the specific methods I used for the speech component of the project. It then presents results from the phonetic analysis and listener assessment.

5.2 Speech materials

I had to decide on suitable materials for read, mood and conversational speech tasks. I present my considerations and decisions for each in turn.

For the oral reading task, it was essential to have a standardised set of sentences for all participants to read. These sentences had to contain sufficient tokens of the phonetic features required for the measures outlined in section 5.5. In brief, these tokens were /i/, /a/ (as in 'park') and /u/ vowels, word-initial /s/ and word-initial /tu/, /tɛ/, /kɒ/, /pɒ/ and /pɑ/ syllables. An example word containing each of these syllables would be 'too', 'telephone', 'contrast', 'population' and 'park'. It was important that the sentences did not contain words that would be unfamiliar to participants. I decided it would be advantageous to use published material. While exploring the Speech and Language Therapy resource room at UEA, I found the Assessment of Intelligibility of Dysarthric Speech (AssIDS) (Yorkston and Beutelman, 1981). After reading the supporting documentation, I saw that this assessment contained phonetically balanced sentences consisting of high and moderate frequency words.

I decided that this assessment would be suitable for my purposes. I decided that I would only use sentences of between five and 12 words in length. I then constructed a matrix to investigate which combination of sentences would achieve the optimal solution in terms of phonetic features. The only constraint was that the final sentence list had to contain two sentences of each of the eight lengths from five to 12 words. I derived the final sentence list and re-ordered it so that the first and last sentences were matched for length. I chose a medium length of eight words. When I examined the final sentence list, I found an Americanism that would be relatively unfamiliar to my participants. Therefore, I changed 'parking lot' to 'car park'.

Subsequent to the study completion, I was advised that 'telephone booth' may not be a term which is used in British English, being an Americanism or Australianism.

Potentially, 'telephone box' is more common in Britain, although it does not have the desired phonetic features. 'Telephone booth' did not appear foreign to me and no participant mentioned it as problematic. The final sentence list can be found in Appendix 34.

For the mood task, I wanted to replicate the findings of an extant small study (Miller et al., 2008a). Therefore, I decided to use the same sentences. However, the design outlined in section 5.6.3.2 required four sentences, whereas Miller's design only used three sentences as a result of containing an additional silent video condition. Therefore, I created an additional sentence using the same criteria; that is that the sentence contains words of moderate to high frequency and does not have an intrinsic emotional association with happy, sad or neutral. The final sentences can be found in Appendix 34.

For the conversational speech task, I considered whether to give a set topic. I decided to let participants choose their topic, as I believed this would lead to the most natural conversation. In the event that participants found it difficult to come up with a topic, I made suggestions based on what they had talked about to me at the start of the appointment. Another advantage of allowing participants to choose their own topic was that it avoided contextual predictability, which could have been a bias in listener assessment, if a small number of set topics had been used. I made a transcript of the conversations from recordings. In cases where I was not sure of my decision, I sought a second opinion from Dr Horton who is an experienced speech and language therapist and clinical researcher.

5.3 Recording techniques

Recording in the field can be challenging and requires careful planning (Ladefoged, 2003). When deciding on the recording set-up for my study, I had to consider four main factors. The equipment had to be portable so that I could transport it to participants' homes. It had to be able to run off battery power with sufficient usage time in order to complete three study appointments without recharging. It had to be of sufficiently high quality to provide an audio track suitable for phonetic analysis (Rutter and Cunningham, 2013).

I decided against the idea of using different audio recordings for phonetic analysis and listener assessment. This reduces the risk of confounding when assessing the relationships between speech acoustics and intelligibility. A potential alternative was to record the audio separately from the video and to merge this audio onto a silent video

track for listener assessment. However, I decided to reject this idea because of potential synchronisation issues. Even a minor lack of synchronisation of audio and video could have significantly confounded listener assessment. Additionally, the equipment cost was constrained by my project budget.

I organised meetings and testing sessions in order to explore and evaluate the available equipment. I tested my own equipment but found that the line-in connection to my laptop was excessively prone to electrical interference in order to reliably provide recordings of the requisite standard. The directionality of my microphones was also very strong, which would have been problematic with participants with dyskinesia. I also did not have a suitable video recorder.

Therefore, I had to contact other people at UEA in order to investigate what high quality recording equipment I could source at an acceptable price. Ideally, I would have used professional recording studio standard equipment. However, none could be sourced at an acceptable price. I am most grateful to Mike Stevens, formerly of the School of Rehabilitation Sciences, for allowing me to borrow audio-visual equipment from the school's collection for an extended period of time free of charge. Mike also provided in-depth training on video recording and editing prior to the launch of my study. I am also grateful to John Thompson of the School of Rehabilitation Sciences for allowing me to retain the equipment following Mike's retirement. Panasonic NV-GS17 (Panasonic Corporation, Osaka, Japan) video cameras were used. The equipment available was of a standard to be used on placements by undergraduate Speech and Language Therapy students. All members of the study management group were satisfied with the quality of recordings obtained.

Prior to commencing study appointments, I had to plan the most appropriate recording techniques. In doing so, I had to achieve a result that was both optimally natural for participants and would achieve high quality technical results. I drew on my own experience in sound recording and post-production, both in academic and musical contexts, as well as consulting other experts.

On arrival at each study location, I assessed the furniture layout and where participants had chosen to sit, and derived the optimal recording set-up based on the following principles. Where possible, it was important to avoid participants having to move. It was important to standardise microphone distance as far as possible. This was approximately 1.5 metres, which is the distance across a medium size dining or conference table. Due to PD-related dyskinesia and the requirement to integrate audio and video streams for listener assessment, the use of body-mounted microphones would

not have been appropriate. Where possible, it was advisable to avoid shooting towards a window, although where necessary, backlight compensation settings could be used.

Field linguistics expert Peter Ladefoged (2003) advises that when recording in the field, it is important to find a quiet place. Doors should be closed and where possible a location away from, for example, waterfalls, trees, waves and animals should be chosen. While, I sought to find optimal recording conditions, one disadvantage of recording in the field is reduced control over environmental variables (Rutter and Cunningham, 2013). Even rain or traffic can affect recordings. Only on two occasions recording in the field, did I have to exclude a recording for quality reasons. One was as a result of traffic noise and the other as a result of animal noise. As discussed in section 4.5, it was important to offer participants the opportunity to be visited at home. No specialist sound-proofed phonetics laboratory was available at UEA. Recording at the university was considerably more challenging in terms of environment than recording in the field (see section 4.5).

It was important for participants to sit in a layout that was natural for them, whether that was next to each other or opposite. In a situation where participants were seated opposite each other, each person was recorded by a video camera placed over the other person's shoulder. If participants appeared unsure as to which camera was recording whom, I clarified this before starting recording.

If participants were seated next to each other, a single camera was used for the read sentences and its positioning adjusted to focus on the person speaking. For the conversation, where possible two cameras were used positioned next to each other at different angles to optimally capture each speaker separately. When recording conversations, no offsetting was used. This is a technique used in many interview recording situations. It facilitates merging the two video streams, with the result that the two people appear to be looking at each other when the interview is broadcast. However, in my study, the speech of each participant was analysed separately. Therefore, this technique was not suitable.

Audio-visual recordings were made using the high quality setting on the video camera. Video files to be used in listener assessment were stored in uncompressed AVI format sampled at 48 kHz. Audio files were extracted for phonetic analysis and re-sampled at 44.1 kHz into high quality WAV audio format. These are the standard high quality sampling rates for audio in video and pure audio respectively. Conversion was required to confirm to the technical standards of the software used for audio and video editing. The conversion of 48 kHz audio embedded in a video file to 44.1 kHz WAV audio

involves a minor reduction in sampling rate rather than bit rate compression. Huckvale (2013) recommends the use of uncompressed files for phonetic analysis.

5.4 Phonetic analysis

5.4.1 Rationale for use

Phonetics is the branch of linguistics which is concerned with the production, transmission and perception of sound to convey meaning and emotion in speech. Phoneticians use a notational convention called the International Phonetic Alphabet to transcribe sound independent of spelling, since in many languages, including English, there is far from a one-to-one correspondence between sounds and letters. Moreover, these correspondences differ between languages. I have used this convention throughout this thesis. Although it should be relatively familiar to many readers due to its frequent use in dictionaries, I have provided examples to illustrate key points. A more detailed explanation of the notation can be found in Wells and House (1995) or on the International Phonetic Association micro-site, currently hosted on the website of University College London (International Phonetic Association, Undated).

Acoustic phonetic analysis is a method which draws on concepts from physics and applies them to speech. It provides objective, quantitative data on continuous scales, which are suitable for parametric statistical analysis (Huckvale, 2013). It is also applicable to any quantifiable aspect of the speech signal. Therefore, it can be used to characterise a wide range of aspects of speech.

5.4.2 Purposive sampling

Since speech analyses were to be conducted on 20 participants per group, I had to decide how selection decisions would be made. Following discussion with phonetics supervisor Dr Butterfint, I decided to use purposive sampling. The reasons for this decision were to achieve an optimal gender by severity matrix and to reduce between-group demographic differences (see section 4.4.7). I also sought to use participants with a familiar CP where possible (see section 4.4.4).

Initially I created a characteristics table with PwPD in the left column and their CPs in the right column. I sorted the dataset by the age and speech severity of the Parkinson's participants. CPs were aligned with their respective PwPD in the dataset. I excluded any recordings with significant quality problems from consideration. I then considered the remaining recordings to derive the optimal solution. As far as possible I sought to use the same participants across tasks.

I included all PwPD with moderate or severe speech impairment due to their underrepresentation in the full study sample. Selection decisions could be made with regard to participants with mild speech impairment. I decided to include younger PwPD where possible. In the full study sample, CPs were on average six years younger than PwPD. More detailed profiling analysis revealed that this difference resulted from a considerably higher proportion of participants under the age of 50 in the CP group. Therefore, I aimed to include CPs under the age of 50 in speech analyses only when they were matched to younger PwPD. I also sought to include the underrepresented gender in each group where possible. I also took accent into consideration. I wanted to have both a good range of accents in each group and reasonable between-group equivalence. In the full study sample, PwPD were more likely to have a Standard Southern British English accent and more CPs spoke Estuary English. The following tables show the results of this purposive sample. They are followed by a commentary evaluating the success of this procedure.

Table 5: Demographic characteristics of people with Parkinson's disease and conversation partners included in speech analysis

		PwPD_b	CPs
N		20	20
Age		71.15 (9.02)	69.75 (10.40)
Age groups			
	≤50	0 (0%)	1 (5%)
	51-60	0 (0%)	1 (5%)
	61-70	9 (45%)	8 (40%)
	71-80	8 (40%)	8 (40%)
	81-90	2 (10%)	1 (5%)
	≥90	1 (5%)	1 (5%)
Gender:			
	Male	13 (65%)	7 (35%)
	Female	7 (35%)	13 (65%)
Smoking status:			
	Never	11 (55%)	9 (45%)
	Past	8 (40%)	7 (35%)
	Current	1 (5%)	2 (10%)
	No answer	0 (0%)	2 (10%)
Accent:			
	SSBE	10 (50%)	10 (50%)
	Estuary	1 (5%)	2 (10%)
	E Anglia	4 (20%)	4 (20%)
	Midlands	0 (0%)	1 (5%)
	Northern	3 (15%)	2 (10%)
	Scottish	2 (10%)	1 (5%)
	Welsh/West	0 (0%)	0 (0%)
Education:			
	No formal	7 (35%)	3 (15%)
	GCSE*	1 (5%)	6 (30%)
	A Level*	2 (10%)	1 (5%)
	Vocational	7 (35%)	8 (40%)
	Undergraduate degree	3 (15%)	0 (0%)
	Postgraduate degree	0 (0%)	2 (10%)
Employment:			
	Professional	8 (40%)	9 (45%)
	Administrative management	5 (25%)	4 (20%)
	Technical and practical	5 (25%)	3 (15%)
	Services and administration	2 (10%)	4 (20%)
	Elementary	0 (0%)	0 (0%)

SSBE= Standard Southern British English, *= or equivalent, _b= for read tasks one substitution was made. The effect of this is discussed below.

Table 6: Clinical characteristics of people with Parkinson's disease included in speech analyses

N	20
PD duration (years)	9.00 (9.50) ^a
MoCA	22.16 (3.27)
HADS	9.55 (4.80)
LEDD	691.50 (1027.25) ^a
Speech severity:	
Male	
Mild	6 (46%)
Moderate	5 (38%)
Severe	2 (15%)
Female	
Mild	5 (71%)
Moderate	1 (14%)
Severe	1 (14%)
All	
Mild	11 (55%)
Moderate	6 (30%)
Severe	3 (15%)

^a = median (IQR) rather than mean (SD)

Before evaluating the success of purposive sampling, I will discuss the one sampling substitution it was necessary to make between tasks. In order to fulfil purposive sampling criteria, it was necessary on one occasion to use one PwPD for read tasks and another for the conversational task. The participant included in read tasks did not have a familiar CP, whereas the participant included in the conversational task was not suitable for read task analysis due to a significant visual deficit and noise from paper shaking. The data from the conversational sample are presented above.

The two participants were both male and had mild speech impairment. They both had accents which were classified for the purposes of this study as northern, although one was a County Durham accent and the other was a Northumbrian accent. These are at the same end of the northern spectrum, both being north-eastern. Their ages differed by only one year. However, there were greater differences with regard to cognitive status, disease severity and depression status. For the sake of clarity, the evaluation of purposive sampling below will consider the sample used for the conversational speech task.

Purposive sampling successfully reduced the average age difference between groups from six years to one year and eliminated the difference in age profiling. It did not

alter the overall gender balance; however it considerably improved the speech severity and speech severity by gender profiles in the PD group. Fifty-five per cent of PwPD in the purposive sample had mild speech impairment. This would appear more representative of the target population than 71% in the full study sample. Purposive sampling achieved two groups closely matched for accent, while retaining the wide range of accents which is a strength of this study. It did not have any detrimental impact on any other participant characteristics. Therefore, the purposive sampling can be considered successful.

5.4.3 Analysis software

Relatively recent technological advances have armed phoneticians with an array of accessible analysis software which can be run on standard computer operating systems. However, considerably different absolute parameter values can be obtained using different software (Maryn et al., 2009, Smits et al., 2005). The three most commonly used speech analysis programs in studies on speech disorders are Praat (Paul Boersma and David Weenink, Phonetic Sciences, University of Amsterdam), Computerized Speech Lab (Kay Elemetrics Corporation, Lincoln Park, NJ) and the Multidimensional Voice Program (Kay Elemetrics, Corporation, Lincoln Park, NJ). I did not consider the Multidimensional Voice Program since it is a voice-specific program, whereas my study assessed a wide range of speech parameters.

So far no comprehensive comparison of the relative strengths and weaknesses of different phonetic software has been published. In the absence of any contraindication, I decided to use Praat. Computerized Speech Lab is commercial software that the UEA did not have. I considered Speech Filing System (Mark Huckvale, Division of Psychology and Language Sciences, University College London), which I have used previously and was developed by my Master's degree course tutor. However, I decided it was important to use software which phonetics supervisor Dr Butterfint uses on a regular basis, for reasons outlined in section 5.5.5.

5.4.4 Measures

I used phonemic notation to refer to speech sounds in so far as they contrast with other sounds to form different words. For example, 'park' is notated as /pɑ:k/, whereas 'bark' is notated as /bɑ:k/. The use of slanted (phonemic) rather than square (phonetic) brackets indicates that sounds are being referred to in an abstract contrastive sense, rather than in terms of their precise phonetic properties. The use of this notation in my thesis is purely for descriptive purposes and bears no theoretical connotations. My thesis

does not suppose the psychological reality, or use in speech production and perception, of abstract sound units such as phonemes. Roach (2001) defines a phoneme as “a speech sound which can be identified as one of the set of distinctive sounds of a particular language”. Although the notion of phonemes remains pervasive in some linguistic circles, several theorists have provided evidence to the contrary (Coleman, 1998, Hawkins, 1995, Pisoni, 1997, Hawkins and Smith, 2001).

5.4.4.1 Measure selection

I sought to include phonetic measures covering a range of aspects of speech that I considered potentially relevant to speech impairment in PD. I identified four key broad domains. These were initiation, prosody, voicing and articulation. Initiation relates to the production of airflow. Prosody refers to the rhythm and melody of speech. Voicing relates to the generation of a periodic sound source through the vibration of the vocal folds, allowing the distinction between sounds such as /s/ and /z/. Articulation refers to the modification of sound waves produced by the sound source by the resonant properties of the vocal tract. Different speech sounds use different vocal tract configurations. This is called the source-filter theory (Fant, 1981).

Measures of initiation were intensity and intensity decay. Intensity was a measure of the mean amplitude in decibels sound pressure level (dB SPL) across the sentence. We perceive intensity as loudness. I calculated intensity decay as:

$$Intensity\ decay = 100 \left(\frac{intensity\ first\ sentence - intensity\ last\ sentence}{intensity\ first\ sentence} \right)$$

It provided an indication of whether the speech intensity of PwPD declined more rapidly than CPs as a result of increased vocal fatigue. Reduced vocal intensity and increased intensity decay have been demonstrated in PD (see section 2.4.2.2).

Measures of prosody were mean fundamental frequency (MnF₀), standard deviation of fundamental frequency (SDF₀), rate, adjusted rate, acceleration, adjusted acceleration, pause, within-word pause, iteration and within-word iteration. Sections 2.4.2.1 and 2.4.2.4 show that impairments of a range of prosodic aspects of speech have been found in PD. Therefore, I decided to include these measures in my overview of speech and communication in PD. In this broad classification, I have included all aspects of rhythm and fluency under prosody.

Fundamental frequency (F₀) refers to the number of vocal fold cycles produced per second. It is perceived as pitch. SDF₀ is an overall measure of pitch variability, which

provides an indication of how much inflection the speaker uses. I conceptualised speech rate in terms of syllables per second, although words per minute can also be used. An advantage of syllables per second is that it is robust to word length effects. I calculated acceleration, which is a measure of change in speech rate over a sentence list or conversation, using the following formula:

$$Acceleration = 100 \left(\frac{rate\ last\ sentence - rate\ first\ sentence}{rate\ first\ sentence} \right)$$

I also calculated adjusted versions of these rate and acceleration measures, in order to remove the effect of dysfluency. Dysfluency time (pauses, iterations and fillers) were excluded from the speech time, and iterated syllables were excluded from the syllable count in these calculations. Now I shall explain how I calculated pause and iteration measures. Pause was calculated in milliseconds (ms) and expressed as a percentage of the utterance time. A 50 ms threshold was used as the minimum significant pause duration. A variety of thresholds for pause have been used in previous studies both in PD and in studies of other medical conditions and second language acquisition. There has been a long-standing debate regarding the boundary between articulation and hesitation pauses. Authors such as Goldman-Eisler (1968) have suggested a cut off of 250 ms to differentiate between these two types of pause. Some studies, for example Iwashita (2010), have used pause thresholds as high as 1000 ms. However, research has demonstrated that most pauses in the 130-250 ms range (Hicke et al., 1983) and some as short as 60 ms (Campioni and Véronis, 2002) cannot be seen as articulatory, but rather should be seen as hesitation pauses. Indeed, in the context of PD, Skodda and Schlegel (2008) used a particularly short threshold for pause of 10 ms. I selected a 50 ms threshold in order to provide what I considered optimal balance between a threshold that is sufficiently short in order to allow a fine grained analysis but not so short as to include pauses that are not likely to be associated with hesitation.

I additionally calculated a measure of within-word pause, as the percentage of pause that occurred within rather than between words. It was not possible to include pauses prior to voiceless stops since the potential pause cannot be reliably separated from the stop closure. Iteration refers to the repetition of a linguistic unit such as a phrase, word or part of a word (morpheme or phoneme). I calculated the number of instances of linguistic unit repetition. Additionally, I calculated a measure of within-word iteration, as the percentage of instances of iteration that occurred within rather than between words.

Measures of voicing were jitter, shimmer and harmonic-to-noise ratio (HNR). As discussed in section 2.4.2.1, voicing impairments are believed to be among the most

prevalent and earliest speech signs of PD. These measures are widely used traditional measures of voicing. The exclusion of the Cepstral Peak Prominence is explained in section 5.4.4.2. Jitter and shimmer were expressed as percentage rather than raw values. Jitter relates to the relative percentage variation in the glottal cycle duration, shimmer to the relative percentage variation in glottal cycle amplitude and HNR to cycle-to-cycle variation in waveform shape (Huckvale, 2013). HNR is therefore a measure of the strength of harmonics in the vocal signal.

Measures of articulation were Formant Centralization Ratio (FCR), /s/ amplitude standard deviation (/s/ SDA) and voice onset time ratio (VOTr). FCR is a relatively novel measure that has been shown to be more sensitive than the Vowel Space Ratio to reduced vowel contrastiveness in PD using American English, and not to be subject to significant gender effects (Sapir et al., 2010). I decided to assess its transferability to British English since it is possible that the vowel system of British English may be more suitable to characterisation in terms of four rather than three unrounded ‘corner’ vowels. For the sake of clarification, a formant in this context refers to peaks in the speech spectrum (Fant, 1970), that is to say frequency regions in the speech signal that have been particularly emphasised by the vocal tract configuration for the particular sound. Formants are often notated as for example F1 for first formant and F2 for second formant. This notation is used in the following formula demonstrating how I calculated FCR:

$$FCR = \frac{F2u + F2a + F1i + F1u}{F2i + F1a}$$

I also decided to include /s/ ASD as a measure of consonant articulation quality. Some PwPD have difficulty maintaining sufficient sub-glottal pressure to produce stops with sufficient closure and fricatives with sufficient and consistent power. Increased /s/ ASD could indicate difficulty in pressure maintenance. Chen and Stevens (2001) found that people with dysarthria differed significantly from controls with regard to time variation in the acoustic pattern and with regard to the spectral shape of initial /s/. A strong association with intelligibility was found. Segment boundary decisions are discussed in section 5.4.4.3.

VOTr is a measure of the extent to which a speaker contrasts phonologically ‘voiced’ and ‘voiceless’ sounds, for example the distinction between ‘park’ and ‘bark’. The consonant-vowel contexts I chose for my study are discussed below. Voice onset time is traditionally defined as the time between the release of the oral constriction for stop production and the start of vocal-fold vibration (Zlatin, 1974, Lisker and Abramson, 1967). However, this measure is subject to speech rate effects. Therefore, Fischer and Goberman (2010) suggested using VOTr, which they conceptualised as the voice onset

time divided by the summated duration of the voice onset time, closure and vowel. Due to the difficulty in defining stop closures precisely in dysarthric populations, I decided to modify VOTr and used the following formula. Segment boundary decisions are discussed in section 5.4.4.3:

$$VOTr = \frac{\text{voice onset time}}{\text{voice onset time} + \text{vowel duration}}$$

For segmental measures, I made the following decisions regarding contexts in which measurements should be made. For VOTr analysis, I decided to use only word-initial stops not in consonant clusters. Voice onset time has been shown to vary as a function of phonetic context (Lisker and Abramson, 1967, Abdelli-Beruh, 2004) and place of articulation (Byrd, 1993). Therefore, I sought to use a range of initial consonant-vowel combinations (/pɒ/, /tɛ/, /pɑ/, /t:/ and /kɒ/) and analysed each separately. For /s/ SDA, I used initial /s/ not in consonant clusters. A theory development article (Hawkins and Smith, 2001) cited an example of different morphological structure in the words ‘mistimes’ and ‘mistakes’ on voice onset time and /s/ duration. My Bachelor of Arts preliminary dissertation (Barnish, 2006) investigated this phenomenon using three ‘dis’ pairs as well as the ‘mis’ pair spoken by five male Southern Standard British English speakers. I found significant differences in /s/ duration for one pair of sentences with a marginally significant result for two others, and statistically significant differences in voice onset time for all but one pair. These studies provide evidence for an influence of context on the acoustic characteristics of /s/. Therefore, I decided to use tokens of /s/ produced in a relatively similar phonetic environment. It was not possible to control for following vowel identity using the sentences available in AssIDS (see section 5.2). For vowel analyses, I decided to use non-diphthongal /ɑ/, /i/ and /u/ vowels in stressed syllables. Unstressed syllables were not used because they have been shown to be associated with reduced phonetic distinctiveness (Low et al., 2000, Sugahara, 2007).

5.4.4.2 Practicalities

There were some practical limitations on the phonetic analyses that I could conduct as part of this multi-faceted PhD study. As discussed in section 5.2, it was necessary to limit the sample size for speech analyses to 20 PwPD and 20 CPs. Additionally, time constraints and the fact I was the sole analyst (except for a 10% reliability check as described in section 5.4.5) meant that it was not possible to include some measures. Only sentence-level parameters could be analysed for conversational sentences. In addition to time constraints, contextual variability as a result of non-

standardised content would have posed considerable difficulty for the interpretation of analyses conducted at the level of the individual sound or syllable.

I considered including the Pairwise Variability Index (Low et al., 2000) as an additional measure of rhythm. It would have offered a more global perspective on potential dysfunction of rhythmic structure than measures of pause and iteration. However, it is a highly resource-intensive analysis that requires the duration of each vowel in a sentence to be calculated.

I also considered including the Cepstral Peak Prominence as an additional measure of voice. A cepstrum (Oppenheim and Schaffer, 2004) is the result of performing an inverse Fourier transform on the logarithm of a signal spectrum. It is essentially a mathematical abstraction. The Cepstral Peak Prominence is the most prominent resonance of this cepstrum, and has been suggested as a more sensitive and reliable measure of dysphonia than traditional parameters such as jitter and shimmer (Hillenbrand et al., 1994, Heman-Ackah et al., 2002, Heman-Ackah et al., 2003). However, calculating cepstral peak prominence would have involved the use of a command line program, separate from the program used for other phonetic analyses. There is evidence that absolute phonetic values are not always comparable across different software (Maryn et al., 2009, Smits et al., 2005). Additionally, interpreting results in the cepstral domain is problematic without advanced mathematical training. Therefore, I did not include these two measures in my phonetic analysis.

5.4.4.3 Measurement criteria

A summary of the key criteria I used is provided here. Further detail, rationale and explanation can be found in Appendix 33. A vowel was defined as lasting from the first downward zero-crossing after the start of periodic voicing until the first upward zero-crossing following the cessation of periodic voicing. When defining vowels, it was important to remember that I was defining the specific vowel of interest, rather than the total period of voicing. Boundaries between nasal and non-nasal segments are often characterised by sharp changes in amplitude and formants, as seen on the spectrogram. Fricatives were measured from the first downward zero crossing after the start of aperiodicity to the first upward zero crossing after the resumption of periodicity. Stops were measured from the transient burst until the first upward zero crossing after the resumption of periodicity.

5.4.5 Reliability assessment

I asked Dr Butterfint to reassess 10% of my phonetic data independently, blinded to group membership. The same analysis methods were used as in 5.5.4. Upon receipt of the data, I performed reliability analysis using PASW statistics version 18 (SPSS Inc, Chicago, IL) software. For reasons of statistical power, I pooled groups of related phonetic measures. Following discussion with statistics adviser Dr Clark, I conducted a two way mixed single measures intraclass correlation.

The intraclass correlation has been shown to be equivalent to weighted kappa as a measure of reliability (Fleiss and Cohen, 1973). Shrout & Fleiss (1979) outline which intraclass correlation coefficient should be used in which circumstances. Interrater reliability assessment can take three forms. In the first, each target is rated by a different set of judges randomly sampled from a larger population of judges. In the second, each target is rated by the same set of judges selected from a larger population. In the third, each target is rated by the same set of judges who are the only judges of interest.

The phonetics interrater reliability assessment falls under the third category, in which raters are considered fixed effects rather than random effects. This requires analysis using a two-way mixed intraclass correlation coefficient. Since there is only one judge in each group, the more conservative single measures method must be used rather than the average measures method. If $r < 0.70$ for any phonetic measure, I performed an additional intrarater reliability assessment involving the re-evaluation of ten tokens. Results are presented in section 5.7.1.

5.4.6 Evaluation of phonetic analysis

Phonetic analysis was completed successfully. Reliability assessment returned satisfactory results. As discussed in section 5.4.4, a small number of intended phonetic analyses could not be completed. However, the analysis included in this thesis constitutes a thorough acoustic investigation of the speech of PwPD using read, conversational and mood tasks.

5.5 Listener assessment

5.5.1 Rationale for use

I wanted to assess potential reduced intelligibility and emotional conveyance in PwPD relative to CPs, as well as the contribution of acoustic characteristics to these

impairments. Since these are psycho-acoustic phenomena, I decided that listener assessment would be the optimal method of investigation. In order to improve generalisability of the findings, I decided to recruit a large panel of non-expert listeners rather than use a small number of expert assessors.

5.5.2 Listener recruitment

5.5.2.1 Recruitment routes

I calculated that to achieve the design in section 5.6.3, I needed to recruit 60 assessors. Due to ethical constraints, all assessors had to be UEA staff or students. Further inclusion criteria are outlined in section 5.6.2.2. Since university students are acknowledged to be a hard to reach group, I had to devise an innovative publicity strategy. I created a multi-faceted publicity strategy with optimal possible coverage. A copy of my poster and press release are included in Appendices 35 and 36.

Posters are a widely used but relatively low-impact strategy. However, I decided that posters should form part of my strategy since poster boards are available in the most locations across campus and they serve to reinforce other advertising methods. I displayed posters in the Schools of Nursing Sciences, Rehabilitation Sciences, Norwich Medical School, Norwich Business School, Environmental Sciences, Chemistry and Pharmacy, Education, Psychology, Language and Communication Studies and Literature Drama and Creative Writing. I also displayed posters in the Centre for Staff and Educational Development, the library, students' union and Hubs (equivalent to department offices).

The press office granted me a press release on the staff and student bulletins. I secured permission for a poster on the school-managed digital screens in the schools of Nursing Sciences and Rehabilitation Sciences respectively. My supervisors uploaded my press release onto Blackboard (e-learning system) and alerted colleagues.

5.5.2.2 Inclusion criteria

As stated above, all assessors had to be members of UEA. It must be acknowledged that the ethical requirement to use university members led to a selection bias towards younger and more highly educated assessors than a random community sample would provide.

The remaining inclusion criteria sought to obtain a listener panel that was as representative of everyday life as possible. Since PwPD usually communicate with people

who are not experts in speech or language, it was important to recruit non-expert assessors. Richardson et al (2011) recognise that expert participant bias can be a problem in many psychology studies. I decided, taking advice from my supervisors who teach in the School of Rehabilitation Sciences, that only final year Speech and Language Therapy students and Speech and Language Therapy staff would be sufficiently experienced in speech disorders to merit exclusion. Other university members who reported significant experience in listening to disordered speech, for example due to having a close family member with PD, were excluded from being an assessor.

All assessors had to be fluent English speakers. However, to be more representative of society, native speaker status was not required. In addition, for ethical reasons, I could not include potential assessors who were currently working with groups or individuals with PD. This was because many of my participants attend PD groups in the region.

5.5.2.3 Process

Interested potential assessors emailed me to register their interest in the study and ask any questions. Replies that were sent to any of my supervisors (Drs Deane, Horton and Butterfint) were forwarded to me for attention. I then emailed a copy of the information leaflet (see Appendix 37) and assessed the inclusion criteria. If potential assessors remained interested and eligible, I offered potential appointment times. Potential assessors then replied to me to confirm which time would be most convenient. I then confirmed the session arrangements. In addition, I sent all assessors an email reminder the day before their scheduled session.

5.5.2.4 Prize draw

As approved by the ethics committee (see section 4.8.8), I offered all assessors the opportunity to enter a prize draw as a gesture of thanks for their time. One prize of a £25 Marks and Spencer voucher as well as five £5 vouchers were offered. Following completion of all listener assessment sessions, I performed a computerised random draw using all completed entries and administered prizes to winners.

5.5.2.5 Recruitment statistics

It is not known how many people read advertisements for my study as the methods used do not provide feedback. I received 84 expressions of interest. Sixty-four assessors participated in the study. Of the 20 people who expressed interest but did not

participate, eight did not reply to correspondence, six had scheduling problems, four were ill, one did not turn up and in one case the study was already complete when I received the reply. Four additional assessors were required in order to ensure each of the 20 composite files was triple-rated for reliability (see section 5.5.3), because four assessors were assigned a file which had been already triple-rated. These extra data were able to be included in the analysis and increased reliability.

5.5.2.6 Demographic characteristics

Table 7: Demographic characteristics of listeners

N	64
Age:	22 (9) _a
Age group:	
18-24	44 (69%)
25-40	13 (20%)
41-60	7 (11%)
≥61	0 (0%)
Gender:	
Male	8 (13%)
Female	56 (88%)
Department:	
Pharmacy	34 (52%)
Rehabilitation Sciences	13 (20%)
Nursing Sciences	9 (14%)
Learning and Teaching Services	3 (5%)
Information Services Division	1(2%)
Language and Communication Studies	1(2%)
Norwich Medical School	1(2%)
Research and Enterprise Services	1(2%)
Vice-Chancellor's Office	1(2%)

a= Median (IQR) not mean (SD)

A university-based sample is not representative of wider society with regard to age and educational status. Staff constituted 11% of the sample, which would be expected given the student-staff ratio and staff workloads. The age profile can be considered reasonably representative of the university membership. The Faculty of Medicine and Health Sciences has the highest (53%) proportion of students over the age of 25, compared to a university average of 30% (University of East Anglia, 2013).

Eighty-eight per cent of assessors were female. The proportion of females in the student population is 58%, which rises to 80% in the Faculty of Medicine and Health Sciences (University of East Anglia, 2013) where this study is based. Data for pharmacy students are not published separately from the Faculty of Science in total, although there is reason to believe they would be relatively similar to the Faculty of Medicine and Health Sciences. Therefore, the selection bias with regard to gender is considerable if the whole university is taken as the target population, whereas it is minor if the schools to which this study is most relevant are taken into account. The distribution of assessors in this study

by department is not representative of the university as a whole and reflects the greater relevance and interest of this study to members of some departments.

5.5.2.7 Evaluation of recruitment

Recruitment of assessors was successful. Target numbers were reached one month ahead of schedule. Recruiting university members as assessors, which was mandated by ethical requirements, introduced a selection bias, which rendered the sample not representative of society in general. However, the sample was relatively representative of the demographic characteristics of the schools, to which this study was most relevant, namely the Faculty of Medicine and Health Sciences and pharmacy students. At UEA, pharmacy shares a school with chemistry, but no chemistry students participated. Although advertising was university-wide, 84% of assessors were students of pharmacy or from the Schools of Nursing Sciences and Rehabilitation Sciences. This reflects the difficulty of recruiting students into research studies that are not directly relevant to their course. Therefore, the study sample was not representative of the wider university population or society in general. The potential effect of this sampling bias on interpretation of results is discussed in chapter seven.

5.5.3 Design and stimulus presentation

After performing purposive sampling (see section 5.4.2), I finalised the design and prepared the stimuli. The details of the design are presented in the following sections. I edited video files using EditStudio (MediaChance, Ottawa, Canada), which is an affordable video editing suite recommended by technical adviser Mike Stevens. Stimulus presentation is discussed in section 5.6.3.3.

I created a matrix for each of the read, conversation and mood designs. Excerpts are included below. Full grids do not fit on standard sized paper but are available in electronic format from me on request. I based each grid on a Latin Square design (Grant, 1948), which applied to this design means that each assessor hears sentences from a wide range of speakers. This approach improves external validity and reduces the potential for speaker learning effects. As discussed earlier, there is evidence that individual speaker characteristics are important for speech perception.

5.5.3.1Intelligibility design

Creating a listener assessment design for read sentences posed particular challenges since all participants read the same 16 standard sentences. Repetition of the

same script sentence could induce a learning bias that would artificially improve performance on repeated presentation. Stimulus exposure effects represent a recognised bias in human psychology experiments (Bornstein and D'Agostino, 1992, Grill-Spector et al., 2006).

The principal challenge in creating the read stimulus design was balancing statistical power, the target assessor sample size and the risk of learning bias. If 60 assessors were used, only ten speakers per group could be used if each assessor heard each script sentence only once. I decided that this would be insufficient to perform the statistical analysis described in section 5.7. For 20 speakers per group to be used and each assessor to hear each script sentence only once, 120 assessors would have been needed. This was unfeasible.

Therefore, as the best balanced solution, following consultation with the study management group, I decided on the following design. Sixty assessors rated 32 read sentences each. Assessors rated each of the 16 script sentences produced once by a Parkinson's participant and once by a CP. Each assessor rated the read speech of 32 out of 40 speakers. No assessor rated more than one read sentence produced by the same speaker. Since each assessor heard each script sentence only twice, the risk of significant learning effects was considered low. Each utterance produced by each of the 20 PwPD and 20 CPs was rated by three different assessors.

Table 8: Excerpt from read sentences intelligibility design

Speaker odd =PD, even =CP	88	35	15	79	7	18
Sentence 1	1,41,21	2,42,22	3,43,23	4,44,24	5,45,25	6,46,26
Sentence 2	40,20,60	1,41,21	2,42,22	3,43,23	4,44,24	5,45,25
Sentence 3	39,19,59	40,20,60	1,41,21	2,42,22	3,43,23	4,44,24
Sentence 4	38,18,58	39,19,59	40,20,60	1,41,21	2,42,22	3,43,23
Sentence 5	37,17,57	38,18,58	39,19,59	40,20,60	1,41,21	2,42,22
Sentence 6	36,16,56	37,17,57	38,18,58	39,19,59	40,20,60	1,41,21
Sentence 7	35,15,55	36,16,56	37,17,57	38,18,58	39,19,59	40,20,60
Sentence 8	34,14,54	35,15,55	36,16,56	37,17,57	38,18,58	39,19,59
Sentence 9	33,13,53	34,14,54	35,15,55	36,16,56	37,17,57	38,18,58
Sentence 10	32,12,52	33,13,53	34,14,54	35,15,55	36,16,56	37,17,57
Sentence 11	31,11,51	32,12,52	33,13,53	34,14,54	35,15,55	36,16,56
Sentence 12	30,10,50	31,11,51	32,12,52	33,13,53	34,14,54	35,15,55
Sentence 13	29,9,49	30,10,50	31,11,51	32,12,52	33,13,53	34,14,54
Sentence 14	28,8,48	29,9,49	30,10,50	31,11,51	32,12,52	33,13,53
Sentence 15	27,7,47	28,8,48	29,9,49	30,10,50	31,11,51	32,12,52
Sentence 16	26,6,46	27,7,47	28,8,48	29,9,49	30,10,50	31,11,51

Columns represent speakers, rows represent sentences and numbers in the main body of the table represent assessors.

When creating a listener assessment design for conversational sentences, I had to decide between two potential emphases, which would have required very different designs. One option was to investigate the effect of context on intelligibility using conversations presented as a whole. The other option was to investigate the effect of cognitive load effects on spontaneous speech production by presenting excised sentences using a design comparable to that for read sentences presented above. I decided in favour of the second option since it was more in keeping with the overall aims of my study.

Due to the wide range of conversational topics (see section 5.2), there was no significant risk of contextual predictability bias. Therefore, each assessor rated ten conversational sentences, each spoken by a different participant. Each assessor rated the conversational speech of five PwPD and five CPs. Each utterance produced by each of the 20 PwPD and 20 CPs was rated by three different assessors. I staggered the speaker sequence from that used in the read sentences to reduce speaker predictability.

Table 9: Excerpt from conversational sentences intelligibility design

Speaker odd =PD, even =CP	54	62	8	79	7	18
Sentence 1	1,41,21	2,42,22	3,43,23	4,44,24	5,45,25	6,46,26
Sentence 2	40,20,60	1,41,21	2,42,22	3,43,23	4,44,24	5,45,25
Sentence 3	39,19,59	40,20,60	1,41,21	2,42,22	3,43,23	4,44,24
Sentence 4	38,18,58	39,19,59	40,20,60	1,41,21	2,42,22	3,43,23
Sentence 5	37,17,57	38,18,58	39,19,59	40,20,60	1,41,21	2,42,22

Columns represent speakers, rows represent sentences and numbers in the main body of the table represent assessors.

5.5.3.2 Emotional conveyance design

The aim of this task was to identify whether the speaker intended to sound happy, sad or neutral, rather than to identify the intended meaning. Therefore, there was no significant problem with sentence repetition. Each assessor rated 48 sentences dispersed across different combinations of script sentence, mood and modality. Each assessor rated 24 sentences spoken by PwPD and 24 sentences by CPs. Each assessor rated a mood sentence from each of the 40 speakers, and rated an additional sentence from eight speakers. Each utterance spoken by each of the 20 PwPD and 20 CPs was rated by three different assessors. I staggered the speaker sequence from that used in the read and conversational sentences.

Table 10: Excerpt from emotional conveyance design

Speaker	90	13	1	79	43	18
odd =PD, even =CP						
S1HA	1,41,21	2,42,22	3,43,23	4,44,24	5,45,25	6,46,26
S1HAV	40,20,60	1,41,21	2,42,22	3,43,23	4,44,24	5,45,25
S1NA	39,19,59	40,20,60	1,41,21	2,42,22	3,43,23	4,44,24
S1NAV	38,18,58	39,19,59	40,20,60	1,41,21	2,42,22	3,43,23
S1SA	37,17,57	38,18,58	39,19,59	40,20,60	1,41,21	2,42,22
S1SAV	36,16,56	37,17,57	38,18,58	39,19,59	40,20,60	1,41,21
S2HA	35,15,55	36,16,56	37,17,57	38,18,58	39,19,59	40,20,60
S2NA	34,14,54	35,15,55	36,16,56	37,17,57	38,18,58	39,19,59
S2NAV	33,13,53	34,14,54	35,15,55	36,16,56	37,17,57	38,18,58
S2SA	32,12,52	33,13,53	34,14,54	35,15,55	36,16,56	37,17,57
S2SAV	31,11,51	32,12,52	33,13,53	34,14,54	35,15,55	36,16,56
S3HA	30,10,50	31,11,51	32,12,52	33,13,53	34,14,54	35,15,55
S3HAV	29,9,49	30,10,50	31,11,51	32,12,52	33,13,53	34,14,54
S3NA	28,8,48	29,9,49	30,10,50	31,11,51	32,12,52	33,13,53
S3NAV	27,7,47	28,8,48	29,9,49	30,10,50	31,11,51	32,12,52
S3SA	26,6,46	27,7,47	28,8,48	29,9,49	30,10,50	31,11,51
S3SAV	25,5,45	26,6,46	27,7,47	28,8,48	29,9,49	30,10,50
S4HA	24,4,44	25,5,45	26,6,46	27,7,47	28,8,48	29,9,49
S4HAV	23,3,43	24,4,44	25,5,45	26,6,46	27,7,47	28,8,48
S4NA	22,2,42	23,3,43	24,4,44	25,5,45	26,6,46	27,7,47
S4NAV	21,1,41	22,2,42	23,3,43	24,4,44	25,5,45	26,6,46
S4SA	20,60,40	21,1,41	22,2,42	23,3,43	24,4,44	25,5,45
S4SAV	19,59,39	20,60,40	21,1,41	22,2,42	23,3,43	24,4,44

Columns represent speakers, rows represent sentences and numbers in the main body of the table represent assessors.
A= audio, AV= audio-visual, H=happy, N=neutral, S=sad, S1 = sentence 1.

5.5.3.3 Stimulus presentation

I decided to present stimuli audio-visually in the intelligibility assessment task, since audio-visual speech perception is more representative of the majority of everyday communicative situations. However, I wished to investigate further the possibility (Miller et al., 2008a) that it could be more difficult to identify the mood people with Parkinson's disease intended to convey when stimuli were presented audio-visually, due to temporal dissonance between auditory and visual cues. Oral speech production is accompanied by discernible facial cues (Bailly et al., 2012), which can aid the perception of certain speech sounds (Bernstein, 2012). It is established in the field of psychology that conflicting visual cues can bias perception even when auditory stimuli alone are unequivocal (McGurk and MacDonald, 1976).

Therefore, in the emotional conveyance assessment task, I introduced modality of presentation as an independent variable, each assessor rating half of their tokens aurally and half audio-visually. I decided to present the listener assessment as two tasks (intelligibility and emotional conveyance) in a fixed order in order to avoid potential assessor confusion, due to fact that the instructions for the two tasks were similar but not identical. Stimulus order was randomised within each of the two tasks in order to avoid any systematic presentation bias. As described in sections 5.5.3.1 and 5.5.3.2, I created 20 file sets using a Latin Square design. Each file set was rated by three different assessors to provide satisfactory reliability. Therefore, 60 assessors were required.

I decided to load each of the 20 file sets into a separate composite video file, which I edited using EditStudio (see section 5.5.3). I inserted instruction titles at the start of each task and a chequered screen of two seconds' duration between each pair of stimuli. This ensured an uninterrupted and even paced presentation of stimuli. Assessors were asked to pause the file between stimuli to write their answers. I decided against inserting a set answer time into the file due to considerable differences in the working speed of different people, which could have left some assessors feeling rushed and others frustrated. Therefore, I decided to allow assessors to pause the file themselves and press play to resume assessment when they were ready. I burnt each of the 20 file sets to a separate DVD disk to be used in assessment sessions.

5.5.3.4 Session logistics

All listener assessment sessions took place in the Communication Laboratory, School of Rehabilitation Sciences, UEA. Prior to advertising for assessors, I booked a series of lab sessions at times which would not impact on the use of the lab for teaching purposes and at which I believed a large proportion of students would be available.

On each study afternoon, I arrived to set the lab up ahead of assessors' arrival. I put an answer book (see section 5.5.3.5) by each assessment station and logged the computers on using a generic login I obtained for the study. I allocated the DVD disks so that each file set was rated three times in total. Before assessors arrived, I pre-loaded the DVD disks so that assessors could start the file by pressing play.

When assessors arrived, I ensured each was sitting at an assessment station. I then gave the session instructions with the help of a power point slide. This included an explanation of why I was conducting the research and what the assessment session involved. I emphasised that assessors should work individually and that for ethical reasons it was important that disks did not leave the room and that if assessors

recognised any participants they must not disclose this to anyone. This last point was especially important as participants lived in the same region as assessors and the diagnosis of PD was implicitly associated with disordered speech. I explained that it was important not to alter the volume level I had set and to expect the speech of some PwPD to be quiet. The capacity limit was 20 assessors per session.

Before the assessment session started, I answered any questions assessors had. I then gave instructions for the completion of the assessor confidentiality agreement (see Appendix 38) and reminded assessors of the opportunity to enter the prize draw (see section 5.5.2.4). I then invited assessors to start the session and said that assessors experiencing any difficulties should put their hand up and I would come and address the issue. When an assessor had finished, I collected the relevant disk and paperwork and the assessor was free to leave quietly. Once all assessors had finished and left the room, I checked the room to ensure no study materials were left behind.

5.5.3.5 Answer books and marking procedures

Since there was no reliable electronic data collection tool available for listener assessment sessions, I created a hard copy answer book (see Appendix 39). The assessment session was presented as two tasks. For the intelligibility task, participants wrote the words they heard on a line next to the question number. For the emotional conveyance task, participants circled the emotion they believed the speaker intended to convey.

Read sentence answers were marked against the sentences presented on large cue cards to participants in the data collection session. If participants said the wrong word, this word was not marked. I took this decision because it was not possible to differentiate between PD related word-finding difficulties and misreading the script for other reasons. Occasional use of wrong words occurred in both the PD and CP groups. Therefore, I believe that in the majority of cases it was simply a misreading. For conversational sentences, answers were marked against the agreed transcript (see section 5.2). For mood sentences, answers were marked against the instructions given to participants, such as for example 'Please say this in a happy way'. I performed all marking.

For the intelligibility task, the outcome measure was per cent words correctly identified (as per Assessment of the Intelligibility of Dysarthric Speech (Yorkston and Beutelman, 1981) protocols). Initially, I calculated scores on a per utterance basis and then calculated speaker means. For the emotional conveyance task, the outcome

measure was per cent moods correctly identified. Initially, I calculated these on a per utterance basis and then calculated speaker means.

5.6 Statistical analysis

Since the analyses presented in this chapter involve group comparisons between PwPD and CPs, it was decided to ask medical statistician Dr Clark to perform the analyses. He conducted analyses using STATA 11.2/SE (StataCorp, College Station, TX) software and met with me to jointly plan analyses and discuss findings. Due to the nature of the dataset, it was not possible to conduct fully blinded analyses. For example, data on cognitive status, disease duration and levodopa equivalent daily dose were only collected for PwPD. Due to the different data structure for PwPD and CPs, it is much more difficult to blind analyses in this context than in clinical trials involving two groups of PwPD. However, it was nevertheless decided that independent analysis would be highly beneficial for study quality. Dr Clark did not listen to the speech recordings or have any interaction with the study participants. This avoided the risk of prior experience of the participants and expected results biasing the conduct or initial interpretation of statistical analysis.

The use of principal components analysis was considered as a means of grouping acoustic characteristics to be regressed against listener outcomes. However, the Kaiser-Meyer-Olkin measure of sampling adequacy (Kaiser, 1970) was insufficient to merit this analysis. It was decided that adjustment for multiple testing was not required for these analyses (Bender and Lange, 2001).

Additionally, it was decided that it would not be appropriate or feasible to use non-parametric analysis or transform variables. Very few distributional complications were found across the variables of interest. It was important to be consistent in the choice of statistical tests. There was no suitable non-parametric equivalent and the use of non-parametric testing would not have been appropriate for the vast majority of variables. The use of logarithmic or root transforms, for example, would have compromised interpretability and introduced distributional problems for the vast majority of variables in my study, for which there were no distributional issues.

Adjustment for repeated measures was incorporated in model construction. The covariates included in each model are outlined below. It was important to balance control of confounders with the number of predictors included in each model. Gender was a key potential confounder in acoustic models. Before presenting the final models, there are some further considerations that I wish to discuss.

When considering how to analyse the results of emotional conveyance listener assessment, there were two potential options. The outcome measure could be conceptualised as per cent mood correctly identified for each speaker, which is a linear measure and could be analysed in the same way as per cent words correctly identified for read sentences. Alternatively, the outcome measure could be conceptualised as a confusion matrix of expected and observed mood values at the utterance level. This would then be analysed using repeated measures multinomial logistic regression. The advantage of the second approach was that it provides a complete confusion matrix. The disadvantages of this approach were that it does not readily provide summary descriptive statistics at a speaker level and that its outputs are not readily comparable with those I used for intelligibility or accessible to a wider readership. On balance, I decided to use the linear conceptualisation.

Forced entry regression models were constructed for the analyses reported in this chapter. It was decided to use forced entry rather than stepwise models in this chapter, since the focus was on the significance of the contribution of each independent variable and interactions between variables, rather than assessing which independent variables were the strongest predictors of outcomes (see chapter 6). For these models, it was decided to construct two categories for MoCA and LEDD. The possibility of dividing MoCA data at the recommended cut-off for suggested cognitive impairment (≤ 26 versus ≥ 27) was considered. However, only two participants in my speech sample scored 27 or higher on MoCA. Therefore, in order to achieve sufficient sample size, it was necessary to split both MoCA and LEDD at the median. Models for read, conversational and mood sentences are presented in turn below. Although the models are structurally very similar, I decided to present them separately here since there are some minor differences in the variable structure.

Firstly, I shall present the models for read sentences. The first set of regression models investigated the differences in the read sentence speech acoustics of PwPD and CPs. The read speech parameters (see section 5.4.4) were included as dependent variables. Group and gender were the independent variables. The interaction between group and gender was assessed.

The second set of regression models investigated the read sentence speech acoustics of PwPD. The read speech parameters (see section 5.4.4) were included as dependent variables. Gender and MoCA were the independent variables. The interaction between gender and MoCA was assessed.

The third set of regression models investigated the differences in intelligibility between PwPD and CPs. Models were constructed with % words correctly identified as the dependent variable and group as the independent variable.

The fourth set of regression models investigated the intelligibility of people with Parkinson's. Models were constructed with % words correctly identified as the dependent variable. MoCA and LEDD were the independent variables.

The fifth set of regression models assessed the relative contribution of acoustic characteristics to the intelligibility of PwPD. Models were constructed with % words correctly identified as the dependent variable. The independent variables were gender, LEDD and speech parameters that were significant for group difference in the first set of models.

Now, I shall present the models for conversational sentences. The first set of regression models investigated the differences in the conversational speech acoustics of PwPD and CPs. The conversational speech parameters (see section 5.4.4) were included as dependent variables. Group and gender were the independent variables. The interaction between group and gender was assessed

The second set of regression models investigated the conversational speech acoustics of PwPD. The conversational speech parameters (see section 5.4.4) were included as dependent variables. Gender and MoCA were the independent variables. The interaction between gender and MoCA was assessed.

The third set of regression models investigated the differences in conversational intelligibility between PwPD and CPs. Models were constructed with % words correctly identified as the dependent variable and group as the independent variable.

The fourth set of regression models investigated the conversational intelligibility of PwPD. Models were constructed with % words correctly identified as the dependent variable. MoCA and LEDD were the independent variables.

The fifth set of regression models assessed the relative contribution of acoustic characteristics to the conversational intelligibility of PwPD. Models were constructed with % words correctly identified as the dependent variable. The independent variables were gender, LEDD and speech parameters that were significant for group difference in the first set of models.

Now, I shall present the models for mood sentences. The first set of regression models investigated the differences in acoustic correlates of happy, neutral and sad mood

between PwPD and CPs. Models were constructed with intensity, mean F_0 , SD F_0 , speech rate, % pause and adjusted speech rate as dependent variables. Group, gender, mood (neutral versus happy) and mood (sad versus happy) were the independent variables. All two-way interactions were assessed.

The second set of regression models investigated the mood speech acoustics of only PwPD. Models were constructed with intensity, mean F_0 , SD F_0 , speech rate, % pause and adjusted speech rate as dependent variables. Gender, mood (neutral versus happy), mood (sad versus happy) and MoCA were the independent variables. All two-way interactions were also assessed.

The third set of regression models investigated the differences in listener measures of emotional conveyance between PwPD and CPs. Models were constructed with % moods correctly identified as the dependent variable. Group, mood (neutral versus happy), mood (sad versus happy) and modality were the independent variables. All two-way interactions were also assessed.

The fourth set of regression models investigated the emotional conveyance of PwPD. Models were constructed with % moods correctly identified as the dependent variable. Mood (neutral versus happy), mood (sad versus happy), modality, MoCA and LEDD were the independent variables. All two-way interactions were also assessed.

The fifth set of regression models assessed the relative contribution of acoustic characteristics to the emotional conveyance of PwPD. Models were constructed with % moods correctly identified as the dependent variable. Gender, mood (neutral versus happy), mood (sad versus happy), MoCA, LEDD, intensity, mean F_0 , SD F_0 , speech rate, % pause and adjusted speech rate were the independent variables. Two-way interactions between mood (neutral versus happy) and MoCA and between mood (sad versus happy) and MoCA were also assessed.

5.7 Results

Here, I shall provide clarification of the directionality of main effect comparisons presented in the following tables. Group refers to CPs minus PwPD. Gender refers to females minus males. MoCA refers to ≥ 24 minus ≤ 23 . LEDD refers to ≥ 607 minus ≤ 606 . Modality refers to audio-visual minus audio.

5.7.1 Phonetic reliability assessment

Table 11: Inter-rater reliability of phonetic measures

Sentence type	Measure	Tokens re-examined	Intra class correlation	P value
	Overall	835	0.994	<0.001
Read	Intensity	27	0.998	<0.001
Read	MnF ₀	27	0.991	<0.001
Read	SDF ₀	27	0.780	<0.001
Read	Rate	23	0.939	<0.001
Read	Jitter	73	0.700	<0.001
Read	Shimmer	74	0.538	<0.001
Read	HNR	74	0.901	<0.001
Read	F1	73	0.849	<0.001
Read	F2	73	0.868	<0.001
Read	/s/SDA	11	0.928	<0.001
Read	VOT	27	0.722	<0.001
Mood	Intensity	68	0.992	<0.001
Mood	MnF ₀	68	0.991	<0.001
Mood	SDF ₀	68	0.940	<0.001
Mood	Rate	65	0.894	<0.001
Conversation	Intensity	19	0.623	0.002
Conversation	Intensity (PD)	9	0.999	<0.001
Conversation	MnF ₀	19	0.995	<0.001
Conversation	SDF ₀	19	0.775	<0.001
Conversation	Rate	19	0.895	<0.001

Table 12: Intra-rater reliability of phonetic measures

Sentence type	Measure	Tokens re-examined	Intra class correlation	P value
Read	Shimmer	10	0.989	<0.001

Phonetic reliability assessment was satisfactory. Overall concordance rate was $r = 0.99$. A concordance rate ($r \geq 0.8$) was found for 68% of measures examined. Concordance rates for only two measures (11%) fell below $r = 0.7$. These are good

results for phonetic analysis which involves a high degree of interpretation and is situated at the interface of the humanities and the sciences.

At the time when I had to submit my recordings for reliability assessment, I had not segmented the conversational audio files produced by CPs into sentences. Only a moderate concordance ($r = 0.62$) was found for intensity of conversational recordings. However, a very high concordance ($r > 0.99$) was found when only conversational recordings spoken by PwPD were considered. Closer examination of the dataset revealed that there was an interrater difference of 13.47 dB on one measurement point. Re-running the intraclass correlation with this data point excluded yielded a very high concordance ($r=0.98$). Therefore, it would appear that the reliability assessor cropped this one sentence in a markedly different way than I had.

The other phonetic measure for which concordance fell below $r = 0.7$ was shimmer. It is difficult to explain the difference in concordance rates between jitter, shimmer and HNR since they are all calculated by the same Praat command and use the same speech selection. A follow-up intrarater reliability assessment on the shimmer measure (see section 5.4.5) yielded a very high concordance of $r = 0.99$ between my first and second ratings, which provides evidence that my analysis of this parameter was reliable.

5.7.2 Read sentence phonetic analysis

Table 13: Phonetic results for read sentences

	PwPD			CPs			Mean difference				
	Male	Female	All	Male	Female	All	Group	Gender	Group * Gender	MoCA	MoCA * Gender
Intensity	59.54 (4.73)	62.27 (4.81)	61.98 (8.22) ^a	63.49 (1.81)	62.90 (2.75)	63.13 (2.39)	4.13*	2.81	-2.89	6.87**	-10.1*
Intensity decay	5.42 (4.72)	5.05 (3.87)	5.52 (4.60)	3.83 (3.34)	3.17 (5.67)	3.43 (4.79)	-1.73	-0.69	0.04	1.55	1.04
MnF₀	137.30 (18.46)	185.80 (25.32)	155.96 (30.83)	116.00 (11.41)	190.10 (27.78)	161.28 (43.38)	-19.80?	42.80***	30.70*	28.70*	1.04
SDF₀	21.36 (8.18)	26.60 (6.09)	23.32 (7.70)	20.73 (6.52)	38.13 (9.26)	31.36 (11.90)	0.95	7.01*	9.63?	6.92?	-14.5*
Rate	3.73 (0.43)	3.83 (0.80)	3.77 (0.57)	4.18 (0.43)	3.54 (0.33)	3.79 (0.48)	0.57*	0.26	-0.92**	0.64?	-0.34
Acceleration	40.28 (31.49)	55.63 (35.22) _a	42.31 (30.06)	51.76 (8.80)	43.94 (14.50)	46.98 (12.90)	9.97	1.19	-9.02	-15.9	-1.85
Adjusted rate	3.90 (0.39)	4.03 (0.69)	3.95 (0.50)	4.27 (0.37)	3.63 (0.31)	3.88 (0.46)	0.38?	0.14	-0.81**	0.48	-0.12
Adjusted acceleration	41.96 (15.37)	50.49 (23.91)	45.16 (18.72)	49.97 (14.63)	48.41 (14.41)	49.01 (14.08)	6.31	3.43	-5.00	-2.19	-15.50
Pause	2.65 (3.86) _a	1.62 (5.52) _a	2.39 (3.84) ^a	0.61 (4.74) _a	2.34 (1.69)	1.40 (3.78) ^a	-5.13*	-4.09?	4.50	-5.23	6.85
Within-word pause	0.00 (4.51) _a	0.00 (6.25) _a	0.00 (4.74) ^a	0.00 (NA) _a	0.00 (0.00) _a	0.00 (0.00) ^a	-2.54?	-0.16	0.68	-2.45	6.26
Iteration	0.00 (0.22) _a	0.45 (0.59)	0.03 (0.41) ^a	0.00 (0.00) _a	0.00 (0.06) _a	0.00 (0.06) ^a	-0.15	0.22	-0.18	-0.22	0.50
Within-word iteration	0.00 (11.81) _a	6.25 (9.94) _a	0.63 (9.36) ^a	0.00 (NA) _a	0.00 (5.20) _a	0.00 (0.52) ^a	-4.94	3.73	-2.00	-5.60	12.10
Jitter /i/	2.43 (0.58)	1.94 (0.74) _a	2.19 (0.78) ^a	2.81 (0.65)	2.24 (0.44)	2.45 (0.58)	0.39	-0.16	-0.42	-0.03	0.49
Jitter /α/	2.07 (1.22) _a	1.73 (0.82)	1.97 (1.50) _a	1.90 (0.60)	1.54 (0.48)	1.67 (0.54)	-0.50	-0.71?	0.36	-0.83	1.77
Jitter /u/	1.76 (0.75)	1.55 (0.68)	1.69 (0.71)	1.98 (0.41)	1.79 (0.83)	1.86 (0.70)	0.18	-0.27	0.09	-0.57	1.08

Shimmer /i/	15.12 (2.28)	13.43 (2.62)	14.53 (2.48)	16.87 (1.70)	14.18 (1.41)	15.17 (1.99)	1.71?	-1.59?	-1.11	-1.67	3.51
Shimmer /α/	15.10 (2.41)	14.67 (2.89)	14.95 (2.52)	17.25 (3.13)	15.20 (2.70)	15.95 (2.96)	2.07	-0.56	-1.49	-0.91	3.73
Shimmer /u/	13.39 (2.75)	11.61 (2.99)	12.77 (2.89)	16.21 (2.90)	12.81 (3.06)	14.06 (3.37)	2.64?	-2.00	-1.40	-1.72	2.84
HNR /i/	8.95 (2.70)	11.55 (2.68)	9.86 (2.92)	7.29 (1.38)	10.43 (1.29)	9.27 (2.02)	-1.58	2.47*	0.67	3.77*	-4.65?
HNR /α/	8.20 (2.66)	9.94 (2.07)	8.81 (2.56)	7.31 (1.49)	10.00 (2.26)	9.01 (2.37)	-0.82	1.69	0.99	4.10**	-6.12**
HNR/u/	11.36 (3.02)	14.25 (2.88)	12.46 (3.28)	9.67 (1.51)	13.24 (2.27)	11.89 (2.72)	-1.68	2.55*	1.02	3.74*	-3.29
FCR	1.37 (0.24) _a	1.37 (0.11)	1.35 (0.18) _a	1.35 (0.09)	1.29 (0.12)	1.31 (0.11)	-0.08	-0.07	0.01	-0.09	0.13
/s/SDA	1.91 (1.37) _a	2.43 (0.83)	2.28 (0.71)	1.87 (0.32)	2.25 (0.36)	2.11 (0.40)	-0.33	0.20	0.19	-0.51	0.78
VOT /pə/	0.24 (0.06)	0.27 (0.08)	0.26 (0.07)	0.27 (0.07)	0.27 (0.06)	0.28 (0.06)	0.02	0.00	0.00	0.03	0.01
VOT /tɛ/	0.37 (0.12)	0.40 (0.06)	0.38 (0.10)	0.40 (0.06)	0.35 (0.08)	0.37 (0.07)	0.03	0.01	-0.07	0.09	-0.11
VOT /pα/	0.18 (0.08)	0.24 (0.08)	0.20 (0.86)	0.19 (0.06) _a	0.16 (0.04)	0.16 (0.04) ^a	0.02	0.00	0.00	-0.01	0.01
VOT /tu/	0.32 (0.07)	0.36 (0.05)	0.34 (0.07)	0.35 (0.09)	0.30 (0.05)	0.32 (0.07)	0.03	0.03	-0.09?	0.05	-0.08
VOT /kə/	0.34 (0.07)	0.34 (0.06)	0.34 (0.07)	0.35 (0.04)	0.32 (0.07)	0.34 (0.06)	0.00	0.56	-0.01	0.07	-0.05

a = Median (IQR) not mean (SD), * = p<0.05, ** = p<0.01, *** = p<0.001, ? = 0.05 < p <0.1.

Due to the presence of significant interactions between variables, main effects have to be interpreted in the context of these interactions.

PwPD had significantly reduced speech intensity relative to CPs. There was no significant gender effect or group by gender interaction. There was also no group difference in intensity decay. This means that both men and women with PD spoke more quietly than CPs, but there was no evidence that the loudness of PwPD decreased more than CPs from the start to the end of the sixteen sentence list. There were significant main effects of MoCA and gender for intensity, as well as a significant MoCA by gender interaction. Men with PD who had higher MoCA spoke more loudly, whereas women with PD who had higher MoCA spoke more quietly.

There was a marginally significant result for increased MnF_0 for men with PD. However, a significant main effect of gender and a group by gender interaction in the opposite direction mean that women with PD had significantly lower MnF_0 than gender-matched CPs. This means that there was a marginally significant result for men with PD to have higher pitch, and that women with PD had lower pitch relative to gender-matched CPs. This appeared to result in a reduction in gender-related pitch differences. PwPD with higher MoCA had significantly higher MnF_0 . There was no significant MoCA by gender interaction. This means that, irrespective of gender, PwPD with greater cognitive impairment spoke with lower pitch.

There was a marginally significant result for reduced SDF_0 for women with PD. This means that there was a marginally significant result for reduced pitch variability in the speech of women with PD, whereas no effect was found for men. Men with higher MoCA score had increased pitch variability, whereas women with higher MoCA score had reduced pitch variability.

Men with PD had significantly increased raw and adjusted speech rate relative to gender-matched CPs. However, women with PD had significantly reduced raw and adjusted speech rate. There was a marginally significant result for PwPD with higher MoCA to speak more quickly, but this was not found for adjusted rate.

PwPD had higher % pause time, with a marginally significant result for higher % within-word pause. No significant differences in iteration or % within-word iteration were found. No significant group by gender interactions were found. No significant associations with MoCA were found for any measures of pause or iteration.

No significant main effects of group or group by gender interactions were found for voice measures or FCR. Marginally significant results were found for higher shimmer for /i/ and /u/ vowels in the CP group. No significant associations with cognitive status were

found for jitter, shimmer and FCR. Men with PD who had higher MoCA scores had higher HNR for /i/ and /a/ vowels. No effect was found for females. For /u/ vowels, there was a significant main effect of MoCA, which descriptive statistics show came from the male participants. However, the main effect of gender was only marginally significant and the gender by MoCA interaction was non-significant. In summary, the HNR findings show that men with PD who had less cognitive impairment had voices with more prominent resonances.

No significant main effects of group, group by gender interactions or associations with cognitive status were found for consonant measures.

5.7.3 Conversational sentence phonetic analysis

Table 14: Phonetic results for conversational sentences

	PwPD			CPs			Mean difference				
	Male	Female	All	Male	Female	All	Group	Gender	Gr*Gen	MoCA	M*Gen
Intensity	57.56 (5.12)	60.92 (5.89)	58.79 (5.51)	61.10 (4.70)	60.28 (4.51)	60.60 (4.47)	3.69	3.56	-4.92	4.73	-9.44?
Intensity decay	1.10 (5.15)	-0.95 (4.56)	0.35 (4.92)	1.32 (3.74)	-0.71 (8.20)	0.08 (6.75)	0.31	-1.57	-0.46	4.58	-3.97
MnF₀	130.47 (16.11)	179.63 (23.50)	145.58 (30.60)	118.44 (21.60)	189.33 (37.94)	161.76 (47.70)	0.39	45.30***	24.00	19.90	-27.50
SDF₀	23.06 (8.75)	27.45 (9.48)	24.68 (9.03)	18.01 (9.78)	33.59 (12.22) _a	30.51 (15.58)	-2.95	7.94?	11.00	-0.46	-12.50
Rate	4.70 (0.64)	4.71 (0.74)	4.70 (0.66)	5.20 (0.52)	4.34 (0.71)	4.67 (0.76)	0.37	-0.19	-0.49	0.25	0.17
Acceleration	25.22 (39.70)	-4.05 (26.71)	14.44 (37.57)	6.88 (30.38)	11.43 (26.25)	9.66 (27.13)	-20.60	-31.00*	35.60	-13.70	6.17
Adjusted rate	4.93 (5.09)	4.96 (0.60)	4.94 (0.57)	5.54 (0.41)	4.62 (0.82)	4.98 (0.82)	0.51	-0.14	-0.65	0.32	0.10
Adjusted acceleration	13.07 (21.93)	-4.42 (20.03)	6.62 (22.42)	2.15 (26.81)	10.57 (22.39)	7.29 (23.80)	-12.60	-19.20?	27.60?	1.15	-5.16
Pause	6.05 (10.59) _a	4.87 (5.40)	4.02 (9.84) ^a	6.50 (4.54)	4.44 (4.17)	4.77 (4.33)	1.01	-0.54	-2.13	-2.74	0.15
Within-word pause	0.00 (NA) _a	0.00 (0.00) _a	0.00 (0.00) ^a	0.00 (NA) _a	0.00 (NA) _a	0.00 (0.00)	0.00	0.90?	-0.90	0.00	1.44
Iteration	0.00 (0.10) _a	0.40 (1.00) _a	0.00 (0.35) ^a	0.34 (0.38)	0.00 (0.40) _a	0.10 (0.40) ^a	0.31	0.72	-0.87**	0.01	0.66
Within-word iteration	0.00 (0.00) _a	0.00 (19.00) _a	0.00 (0.00) ^a	0.00 (10.00) _a	0.00 (0.00) _a	0.00 (0.00)	5.71*	7.38**	-12.30***	0.00	6.47

a = Median (IQR) not mean (SD), * = p<0.05, ** = p<0.01, *** = p<0.001, ? = 0.05 < p <0.1, Gr*Gen = group * gender, M*Gen = MoCA * gender

There was no significant main effect of group or group by gender interaction for conversational sentence intensity. This means that there was no evidence that PwPD spoke more quietly than CPs while taking part in a conversation. No significant main effect of MoCA on intensity was found, although there was a marginally significant result for a MoCA by gender interaction. This suggests there was a marginally significant result for women with PD with higher MoCA to speak more quietly.

There was a marginally significant result for men with PD to have higher adjusted speech acceleration over the course of a conversation compared to gender-matched CPs. There was a significant group by gender interaction for iteration. This means that women with PD iterated more often than gender-matched CPs. With regards to within-word iteration, there were significant main effects of group and gender as well as a significant group by gender interaction. This means that women with PD had increased within-word iteration, whereas men with PD had decreased within-word iteration compared to gender-matched CPs.

No significant group or cognitive effects were found for other conversational speech parameters.

5.7.4 Mood sentence phonetic analysis

Table 15: Phonetic results for mood sentences

	PwPD			CPs		
	Male	Female	All	Male	Female	All
Intensity H	61.71 (5.21)	65.22 (3.61)	63.12 (4.86)	66.55 (2.43)	64.49 (3.57)	65.21 (3.30)
MnF₀ H	168.98 (35.75)	204.39 (28.97)	183.15 (36.96)	155.97 (12.36)	240.15 (28.59)	210.69 (47.56)
SDF₀ H	35.63 (14.04)	43.97 (12.16)	38.96 (13.64)	35.70 (11.54) _a	63.40 (15.94)	55.16 (18.57)
Rate H	4.33 (0.63)	4.18 (0.51)	4.27 (0.57)	4.90 (0.49)	3.90 (0.38)	4.25 (0.63)
Adjusted Rate H	4.46 (0.57)	4.19 (0.51)	4.35 (0.55)	4.91 (0.49)	3.91 (0.38)	4.26 (0.64)
Pause H	0.00 (4.53) _a	0.00 (0.00) _a	0.00 (3.00) ^a	0.00 (0.00) _a	0.00 (0.00) _a	0.00 (0.00) ^a
Intensity N	58.83 (5.33)	60.96 (4.45)	59.68 (4.99)	61.77 (3.46)	60.09 (4.28)	60.68 (4.00)
MnF₀ N	132.84 (19.30)	172.90 (30.85)	148.86 (31.17)	117.66 (13.49)	186.46 (18.23)	162.38 (37.43)
SDF₀ N	18.50 (5.59) _a	29.67 (13.02)	20.82 (9.83) ^a	27.19 (4.31)	34.60 (9.35)	32.01 (8.62)
Rate N	4.45 (0.73)	4.60 (0.65)	4.51 (4.46)	4.77 (0.55)	4.21 (0.28)	4.41 (0.47)
Adjusted Rate N	4.53 (0.67)	4.62 (0.63)	4.57 (0.64)	4.82 (0.54)	4.22 (0.27)	4.38 (0.47) ^a
Pause N	0.00 (1.62) _a	0.00 (0.00) _a	0.00 (0.82) ^a	0.00 (1.14) _a	0.00 (0.00) _a	0.00 (0.00) ^a
Intensity S	57.81 (6.19)	62.15 (3.69)	59.55 (5.65)	62.78 (2.50)	59.88 (4.88)	60.89 (4.36)

MnF₀ S	133.00 (27.26)	172.45 (33.36)	148.78 (35.12)	116.04 (15.11)	186.91 (25.09)	162.10 (40.90)
SDF₀ S	17.83 (8.95) _a	31.64 (9.71)	25.29 (12.06)	23.86 (5.39)	34.60 (11.02)	30.85 (10.65)
Rate S	4.00 (0.74)	3.79 (0.56)	3.92 (0.66)	4.03 (0.64)	3.40 (0.44)	3.62 (0.59)
Adjusted Rate S	4.02 (0.73)	3.80 (0.56)	3.93 (0.66)	4.03 (0.64)	3.41 (0.44)	3.63 (0.59)
Pause S	0.00 (NA)	0.00 (0.53) _a	0.00 (0.00) ^a	0.00 (NA)	0.00 (0.56) _a	0.00 (0.00) ^a

	Group	Gender	Group * Gender	MoCA	Mean difference		Gender * Mood (N-H)	Gender * Mood (S-H)	MoCA * Mood (N-H)	MoCA * Mood (S-H)	Group * Mood (N-H)	Group * Mood (S-H)
Intensity	4.83*	-3.49?	5.54*	1.86	-3.23 ***	-3.58 ***	-0.52	0.02	-1.59	-1.25	-0.97	-0.76
MnF₀	-6.43	41.47***	36.32**	17.27	-32.24 ***	-32.60 ***	-5.10	-4.41	-12.09	-19.34	-12.75	-13.12
SDF₀	9.91*	13.58***	4.44	4.06	-12.03 ***	-11.65 ***	-7.29	-5.08	-7.28	-7.22	-6.37	-9.36*
Rate	0.47?	-0.24	-0.66*	0.65*	0.09	-0.42 ***	0.37*	0.15	0.01	-0.21	-0.17	-0.32*
Adjusted Rate	0.38	-0.32	-0.61*	0.56*	0.07	-0.51 ***	0.37*	0.21	0.03	-0.11	-0.13	-0.26
Pause	-2.03*	-1.85*	0.99	-2.07	-1.27*	-2.56 ***	0.64	1.78*	0.92	1.76	1.14	1.49?

a = Median (IQR) not mean (SD), * = p<0.05, ** = p<0.01, *** = p<0.001, ? = 0.05 < p <0.1.

Men with PD had significantly reduced intensity than CPs. The group by gender interaction shows that the intensity of women with PD did not differ significantly from CPs. This means that men with PD spoke more quietly than CPs, but women with PD did not.

As a result of a significant group by gender interaction, women with PD had significantly decreased MnF_0 relative to controls. This means that relative to controls, women with PD sounded lower pitched. No significant difference was found for men. As expected, across groups women had higher MnF_0 than men.

Both men and women with PD had significantly reduced SDF_0 . As expected, across groups women had a significantly higher SDF_0 than men. There was no significant group by gender interaction. This means that both men and women with PD had less pitch variation in their speech, which may sound more monotonous.

Men with PD had significantly reduced raw speech rate compared to controls. However, the group by gender interaction shows that for women with PD, the effect was in the other direction. For adjusted speech rate, no significant difference was found for males. Women with PD had significantly increased adjusted speech rate relative to controls.

Both men and women with PD had significantly increased pause time compared to controls. Across groups, men had greater pause than women. However, there was no significant group by gender interaction.

In the PD group, there were no significant interactions between gender and mood or between mood and cognitive status. PwPD with MoCA score below median had significantly lower rate and adjusted rate than those with MoCA score above median. This means that PwPD who had more cognitive impairment spoke more slowly.

Main effects of mood were shown within the PD group for all measures except for rate and adjusted rate for the happy versus neutral distinction and rate for the sad versus happy distinction. This means that PwPD were on the whole able to distinguish moods in the acoustic characteristics of their speech, although distinctions were reduced relative to CPs. Two significant group by mood interactions, with three further marginally significant results, for the happy versus sad distinction, suggest that PwPD were particularly impaired in the production of happy.

5.7.5 Read sentence listener assessment

Table 16: Listener results for read sentences

	Parkinson's disease	CPs	Group	Gender	MoCA	Mean difference LEDD	Intensity	Rate	Adjusted rate	Pause
% Correct	81.10 (15.03) ^a	87.92 (3.56)	13.70**	-13.90	9.44	-11.20	2.42*	-47.20	28.30	-3.63*

a = Median (IQR) not mean (SD), * = $p < 0.05$, ** = $p < 0.01$, *** = $p < 0.001$, ? = $0.05 < p < 0.1$.

Listeners were significantly less accurate in transcribing the read speech of PwPD compared to CPs. There was no significant association between the cognitive status of PwPD and listener accuracy. Intensity and pause significantly predicted listener accuracy. This means that listeners were more accurate in transcribing the read speech of PwPD who spoke more loudly and paused less.

5.7.6 Conversational sentence listener assessment

Table 17: Listener results for conversational sentences

	Parkinson's disease	CPs	Group	Gender	Mean difference MoCA	LEDD	Iteration	Within-word iteration
% Correct	55.78 (26.47)	71.94 (13.02)	16.20*	29.00	17.40	-5.61	-20.00	0.67

a = Median (IQR) not mean (SD), * = $p < 0.05$, ** = $p < 0.01$, *** = $p < 0.001$, ? = $0.05 < p < 0.1$.

Listeners were significantly less accurate in transcribing the conversational speech of PwPD compared to CPs. There was no significant association between the cognitive status of PwPD and listener accuracy. No significant associations with acoustic characteristics were identified.

5.7.7 Mood sentence listener assessment

Table 18: Listener results for mood sentences

% Correct	PwPD	CPs										
HA	36.54 (20.50)	55.55 (20.79)										
HAV	54.06 (20.48)	61.36 (13.86)										
NA	55.40 (18.03)	46.70 (18.57)										
NAV	38.50 (25.31)	53.58 (20.78)										
SA	55.80 (21.28)	64.79 (18.68)										
SAV	55.83 (23.10)	62.98 (25.23)										
Mean difference												
	Group	Mood (N-H)	Mood (S-H)	Modality (AV-A)	Modality * Group	Mood (N-H) * Modality	Mood (S-H) * Modality	Mood (N-H) * Group	Mood (S-H) * Group	MoCA	MoCA * Modality	MoCA * Mood (N-H)
% Correct	14.77*	16.11***	13.92**	-2.27	4.54	2.59	8.36	-8.90	-17.82 ***	16.67*	11.54	-8.24
	MoCA * Mood (S-H)	LEDD	Intensity	MnF0	SDF0	Rate	Pause	Adjusted rate				
% Correct	-23.15**	-7.29	-0.04	-0.03	0.26	-39.33	-3.31	39.70				

a = Median (IQR) not mean (SD), * = p<0.05, ** = p<0.01, *** = p<0.001, ? = 0.05 < p <0.1, H= Happy, N= Neutral, S = Sad, A = Audio, AV = Audio-visual

Listener accuracy in mood identification was significantly reduced for PwPD relative to controls. There were main effects of mood for both mood distinctions, indicating that happy mood was the hardest for listeners to identify. A significant interaction between group and mood (sad versus happy) for % correct scores indicates that the impact of PD on listener accuracy was greater for happy mood. Presentation modality did not significantly affect listener accuracy. No significant modality by mood or modality by group interactions were found across groups.

Listener % correct scores were lower for the speech of PwPD who had greater cognitive impairment. Significant mood by cognitive status interactions suggest that the differential effect of PD on happy mood was less for those with more intact cognition.

Listener accuracy in assessing the mood conveyed by PwPD did not differ by speaker gender. Since this set of models was constructed to optimally investigate the association between acoustic characteristics and listener outcomes, it was less sensitive than the analysis presented in the previous table in terms of the effect of mood, LEDD and cognitive status. Therefore, the previously presented data shall take precedence with regard to these parameters. No acoustic characteristics were significantly associated with listener accuracy.

5.8 Overview of results

Satisfactory reliability was demonstrated for phonetic analysis. PwPD, of whom 70% were judged to have mild speech impairment, were shown to be impaired on a range of sentence-level acoustic parameters in read and emotional sentences. Cognitive status and gender played an important role for some acoustic characteristics. Few significant effects were found for phoneme- or syllable-level measures of read speech, or for sentence parameters in conversational sentences.

Listeners were less accurate for PwPD for each of read, conversational and emotional sentences compared to CPs. The cognitive status of speakers only associated with listener accuracy in emotional, not read or conversational sentences. In read sentences, listeners were more accurate in transcribing the speech of PwPD who spoke more loudly and paused less. No significant associations between acoustic characteristics and listener accuracy were identified for conversational or emotional sentences.

5.9 Summary

This chapter initially explored why I chose my speech materials and how I analysed them phonetically. It then detailed the recruitment process, stimulus design and presentation, logistics and marking criteria for listener assessment. Subsequently, it outlined the statistical analysis methods used to analyse phonetic and listener data. It concluded by presenting data and statistical results from my analyses of acoustic speech characteristics, intelligibility and emotional conveyance. The following chapter will address the topic of communicative participation.

Chapter 6: Relationships between cognitive status, speech impairment and communicative participation in Parkinson's disease

6.1 Signposting

This chapter initially describes my validation of the CPIB for use in my study population. It then explains the use of Qualitative Content Analysis and details the method employed. It outlines the statistical analysis methods used for my quantitative analysis. Finally, it presents the results of the communicative component of my project.

6.2 Validating the Communicative Participation Item Bank in my population

As discussed in section 4.6.6, CPIB has been extensively developed in the United States of America (USA) in conditions including PD. A thorough PD cross-cultural validation in New Zealand has also been performed.

These are English-speaking countries and in terms of world culture are broadly at the same end of the spectrum as the UK. There are numerous cultural differences between the USA and UK (Fulbright Commission, Undated). Although New Zealand and the UK are culturally more similar, the former is more outdoors-based (Cloke and Perkins, 1998) and rugby is the major sport (Fougere, 1989). Both countries speak varieties of English that differ from British English in terms of pronunciation and word choice (Bauer et al., 2007, Algeo, 2006).

When taking a questionnaire from one country to another, differences in cultural orientation and word choice can be problematic. People in different countries differ with regard to their habitual leisure activities. Communicative participation relates to people's participation in everyday communicative tasks. Evidently, these are linked. Therefore, it is possible that a communicative participation measure may not transfer well from one country to another, since participants in the other country may not be able to relate to some of the communicative situations. Additionally, if words in the questionnaire are unusual or not used in the other country, it may affect participants' understanding of the questionnaire. If participants have to think hard about what a question means, answers are less likely to be spontaneous. Moreover, if words have a different meaning in the other country, which is also contextually plausible, participants may think they understand the question, but not answer it in the way the researchers intended. Therefore, I decided to perform a UK validation of CPIB as part of my study.

Upon receipt of the draft 46-item CPIB (see section 4.6.6), I distributed it to the steering committee lay representatives. This served several purposes. Firstly, it provided me an indication of how long the questionnaire would take to complete. Secondly, it allowed me to assess whether developing a measure of communicative participation would be of interest to PwPD. One of the lay representatives said that it was an interesting idea and that she had never been asked before how her PD affected everyday communication. Thirdly, it provided an assessment of face validity in its new cultural context. Fourthly, it allowed me to know whether any Americanisms in the questionnaire phrasing would be likely to confuse or appear unusual to participants.

It was decided that, while preferably alterations to the original questionnaire should be minimal, words that steering committee lay representatives believed would appear unusual to participants should be replaced by more familiar British words with similar meaning. Steering committee lay representatives informed me of concerns regarding only one term ('store clerk') which occurred in two questions (questions five and six) on the 46 item CPIB. In British English, the word 'store' is more commonly synonymous with 'storeroom' rather than 'shop'. Additionally, the word 'clerk' is more commonly synonymous with 'secretary' rather than 'shop assistant' in the UK. Especially, as many participants were expected to be older, it was decided to change 'store clerk' to 'shop assistant'. Dr Baylor (C.Baylor, personal communication, 2012) informed me that it had been necessary to alter these items in the New Zealand validation of CPIB. I had not been aware of this at the time of finalising my questionnaire and it was not taken into account in my decision. It transpired that these two items that did not transfer well outside an American English context were not included in the final ten-item CPIB (CPIB10).

No other items were considered problematic by the steering committee lay representatives. Therefore, no other alterations to the questionnaire were made. As discussed below, I sought the views of participants on CPIB and these results are presented in section 6.5.9. Any items considered to be problematic by participants will be discussed in chapter seven.

There were three other questions that contained items which might in my opinion either be slightly unusual or not be understood in the intended sense. Only the question including the term 'movie' was included in the CPIB10.

In question six 'Talking with a shop assistant about a problem with a bill or purchase?', the word 'bill' would be interpreted in the UK as 'amount of money to be paid' (the American term is 'check') rather than '(bank)note'. However, although this is a slightly different sense in its UK meaning than the American meaning, I decided the impact on

the overall question meaning was at most minimal. Querying the amount to be paid or a banknote involve essentially the same communicative skills. Moreover, I decided that the meaning would not be ambiguous to participants. The steering committee lay representatives did not mention this item, evidently understanding it solely in its British sense.

In question 23, the use of the term 'movie' rather than 'film' is considered less of an Americanism than in the past. One of the steering committee lay representatives did mention that it was not something older British people would say, but would be unlikely to cause any confusion regarding meaning. There is a sociolinguistic phenomenon whereby some British English speakers use the term 'movie' to refer to films made in the USA and 'film' to refer to British films, whereas some American English speakers use the term 'film' to refer to foreign and art films, while using 'movie' for mainstream American films. I wanted to maintain original scale items wherever possible and decided there were insufficient grounds to alter this word.

In question 35, none of the steering committee lay representatives or I reported the use of the phrase 'visiting with others in a public place' as problematic. However, after starting the study, I realised I had read it as 'visiting a public place with others', which would be a more usual British phrasing, with a slightly different emphasis on the meaning. The phrasal verb 'to visit with somebody' is not used intransitively in British English, as in 'Visiting with others in a public place'. It is only used transitively, as in 'I visited the park with my friends'. The online Cambridge Academic Content Dictionary (Cambridge University Press, Undated) defines the phrase 'to visit with someone' as an American phrase meaning 'to spend time talking with or staying with someone you know'. However, the intended meaning of this item is very similar to my interpretation using the British phrasing. This item was not included in CPIB10.

A UK validation of CPIB was not the main aim of my study. Therefore, it was performed using the sample recruited for the main study. Recruitment rationale was based upon the requirements of my main speech and communicative analyses rather than being tailored specifically for a scale validation. This is a slight disadvantage of performing a concurrent validation. However, for pragmatic reasons, it was decided to be the best approach in this situation. Due to the moderate sample size and limitations regarding time and resources, it was decided to perform a classical validation rather than using more advanced item response theory techniques.

By means of a classical validation, I assessed test-retest reliability and concurrent validity. Additionally, I decided that it would add another perspective to ask participants

for their comments on the acceptability of CPIB. In order to assess test-retest reliability, I posted another copy of CPIB to participants two weeks after the study appointment (see section 4.5). For an assessment of convergent validity, CES (see section 4.6.6) was used as the comparator scale. It is not ideal that an ICF Activity level scale had to be used as a comparator for an ICF Participation level scale. However, this is a common challenge in emerging areas of research for which few assessment tools are available. It was decided that the concepts were sufficiently related to provide a useful validation for my purposes, and that the use of an Activity level measure was markedly superior to the use of an Impairment level measure. Statistical analysis is discussed in section 6.4. Analysis of qualitative data relating to the acceptability of CPIB is described in the following section.

6.3 Qualitative Content Analysis

6.3.1 Analysis method

When I returned to the university, I typed a transcript of either the participant's written answers or my handwritten notes from oral discussion. I transcribed statements in an ordered list sorted by participant number. I then performed qualitative content analysis (QCA) using a method based on Elo & Kyngäs (2008). Inductive QCA consists of three main phases: preparation, organisation and reporting.

The first stage of preparation is to select the most appropriate unit of analysis. If the chosen unit is too short, this can lead to fragmented analysis. On the other hand, if the unit of analysis is too long, one unit can frequently encompass multiple concepts. This can lead to a loss of detail in the analysis. On balance, I chose the utterance as the unit of analysis. I decided to analyse only manifest and explicit content, rather than latent and implicit content. Then I read through the text twice in order to familiarise myself with the content.

The organisation stage began with open coding. This involved reading through the text and writing notes and headings. As many headings were written as were needed to describe the content fully. Headings were then collated from the margins of the text onto coding sheets. Free concept generation was performed. This completed the open coding stage.

Then the grouping phase was performed. This involved grouping the headings under higher order headings. Categories were created to describe phenomena in the text.

The final phase of organisation was abstraction. This involved combining categories under progressively more abstract categories. This process was ended when

saturation was reached, that is to say when it was no longer sensible or reasonable to continue abstraction.

6.3.2 Establishing trustworthiness

Although the qualitative content analysis described above uses a sequentially structured approach, qualitative analysis is inherently subjective. Therefore, it is important to incorporate a means of establishing trustworthiness.

Graneheim and Lundman (2004) outline three aspects of trustworthiness. The first is credibility, which assesses whether the analysis addressed the intended research question. The second is dependability, which assesses for any changes in the researcher's decision making process over the course of the analysis process. The third is transferability, which assesses the extent to which the findings can be transferred to other groups or settings.

In qualitative research, it is ultimately the reader's decision as to whether results are transferable to their own context (Graneheim and Lundman, 2004). Therefore, in this analysis, which is secondary in regard to my overall thesis aims, I presented the research in its own context and left decisions regarding transferability to the readership. Regarding dependability, Graneheim and Lundman (2004) suggest dialogue within the research team.

There are several aspects of credibility. Patton (1987) and Adler and Adler (1988) suggest that it is important to recruit participants with a range of experiences. Graneheim and Lundman (2004) emphasise the importance of selecting the appropriate unit of analysis. They also state the importance of ensuring that no relevant data have been excluded and that no irrelevant data have been included. A theme to which only one participant contributes must be included, whereas in quantitative methods, the focus is on measures of group central tendency.

I did not recruit my participants specifically for this analysis. However, sections 4.4.7 6.3.4 reveal that participants in my study had a wide range of demographic and clinical characteristics and experiences. When conducting qualitative content analysis, I chose the utterance as the unit of analysis. Shorter units such as the word can lead to fragmented analysis. On the other hand longer units such as the paragraph can encompass multiple concepts and lead to a loss of detail in the analysis.

One method of assessing credibility is peer validation, in which the researcher asks another member of the research team to examine the analysis process and the

resultant concepts, to ensure that they are both internally and externally coherent. The appropriateness of peer validation, which near universally accepted in quantitative research, has been questioned by some authors in relation to qualitative analysis. For example, some theorists such as Sandelowski (1993, 1998) argue that peer validation of qualitative data may not be appropriate, since they argue that there are multiple realities relying on subjective interpretations.

I decided to use an approach based on peer validation. Since this was the first time that I had used qualitative analysis in a research setting, it was important that a more experienced researcher checked my processes and results. I asked experienced qualitative researcher Dr Horton to read my transcript and provide feedback on the coding process and derived concepts. On the basis of his comments, I refined my final concepts. This process ensured credibility of my sample, unit of analysis, consistency of procedure and final themes.

6.3.4 Demographic and clinical characteristics of participants included in QCA

Table 19: Demographic characteristics of people with Parkinson's disease included in Qualitative Content Analysis

		QCA CPIB	QCA Communication
N		29	23
Age		71.79 (8.19)	68.50 (7.75) _a
Age groups:			
	≤50	0 (0%)	1 (4%)
	51-60	1 (3%)	1 (4%)
	61-70	11 (38%)	12 (52%)
	71-80	13 (45%)	8 (35%)
	81-90	3 (10%)	0 (0%)
	≥90	1 (3%)	1 (4%)
Gender:			
	Male	19 (66%)	16 (70%)
	Female	10 (34%)	7 (30%)
Smoking status:			
	Never	16 (55%)	12 (52%)
	Past	12 (41%)	10 (43%)
	Current	1 (3%)	1 (4%)
	No answer	0 (0%)	0 (0%)
Accent:			
	SSBE	18 (62%)	12 (52%)
	Estuary	1 (3%)	1 (4%)
	East Anglia	6 (21%)	5 (22%)
	Midlands	0 (0%)	0 (0%)
	Northern	4 (14%)	3 (13%)
	Scottish	0 (0%)	1 (4%)
	Welsh/West	0 (0%)	1 (4%)
Education:			
	No formal	9 (31%)	8 (35%)
	GCSE*	3 (10%)	4 (17%)
	A Level*	1 (3%)	0 (0%)
	Vocational	9 (31%)	8 (35%)
	Undergraduate degree	5 (17%)	2 (9%)
	Postgraduate degree	2 (7%)	1 (4%)
Employment: %			
	Professional	11 (38%)	7 (30%)
	Administrative management	7 (24%)	9 (39%)
	Technical and practical	4 (14%)	3 (13%)
	Service and administration	7 (24%)	4 (17%)
	Elementary	0 (0%)	0 (0%)

a = Median (IQR) not mean (SD)

Table 20: Clinical characteristics of people with Parkinson's disease included in Qualitative Content Analysis

	QCA CPIB	QCA Communication
N	29	23
PD duration (years)	4.50 (9.00) _a	7.23 (5.30)
MoCA	23.71 (3.13)	22.90 (4.22)
HADS	10.50 (9.00) _a	10.95 (5.87)
LEDD	729.88 (410.15)	629.50 (952.75) _a
Speech severity:		
Male		
Mild	12 (63%)	11 (69%)
Moderate	7 (37%)	4 (25%)
Severe	0 (0%)	1 (6%)
Female		
Mild	8 (80%)	6 (86%)
Moderate	1 (10%)	1 (14%)
Severe	1 (10%)	0 (0%)
All		
Mild	20 (69%)	17 (74%)
Moderate	8 (28%)	5 (22%)
Severe	1 (3%)	1 (4%)

a = Median (IQR) not mean (SD)

I shall now compare the demographic and clinical characteristics of the two QCA samples as a whole with those of the overall study sample. Where relevant, I will highlight differences between the QCA samples. QCA and full study sample participants included were age-similar. In the QCA communication sample, there were slightly more participants aged 61-70 as opposed to 71-80 relative to the other samples. The proportion of men was slightly higher in the QCA samples compared to the full study sample. This difference was greater in the QCA communication sample (70% versus 62%).

The samples were also similar with regards to smoking status and accent profile. The QCA samples, particularly the QCA CPIB sample, had slightly higher educational status than the full study sample. The QCA communication sample had a higher proportion of participants in professional or other managerial occupations.

There were no substantial differences between the samples with regard to cognitive status or depression. Participants in the QCA CPIB sample had on average a shorter disease duration but a higher LEDD. The samples were similar in terms of speech

severity profile, all containing around 70% participants classified as having a mild speech impairment.

6.4 Statistical analysis

Since the quantitative analyses presented in this chapter did not involve group comparisons between PwPD and CPs, blinded analysis was not performed. I met with statistical adviser Dr Clark to jointly discuss the key models and agree a plan. I performed the statistical analysis using PASW statistics version 18 (SPSS Inc, Chicago, IL) software. I decided to use this software due to my previous experience using it and due to the availability of practical training at UEA.

The statistical analysis sought to achieve five main aims. The first was to assess the reliability and validity of CPIB in a UK PD population. The second was to assess the relationship between cognitive status and communicative effectiveness. The third was to assess the relationship between cognitive status (MoCA) and communicative effectiveness (CES) and participation (CPIB). The fourth was to assess which sub-domains of MoCA were most predictive of CPIB score. The fifth was to investigate the relationship between speech impairment and communicative effectiveness and participation.

Prior to finalising the analysis plan, data were assessed for their suitability for the proposed analyses. The Shapiro-Wilk test (see section 4.4.7) was used to assess for normality of distribution. Shapiro-Wilk tests showed no distributional problems with, for example, CPIB10 T score ($SW_{44} = 0.98$, $p = 0.48$), CES ($SW_{44} = 0.97$, $p = 0.39$) and MoCA ($SW_{44} = 0.97$, $p = 0.30$) all showing no evidence of non-Gaussian distribution. CPIB10 T scores were derived following Baylor et al (2013b). As shown in section 6.5.1, all CPIB measures were highly inter-correlated. Dr Baylor recommended that I use either T scores or logit scores for greater cross-study comparability. I decided to use standardised T scores.

In order to assess the convergent validity of CPIB in relation to CES, I decided to perform a Pearson's product-moment correlation. In order to assess the test-retest reliability of CPIB, I performed an intraclass correlation (see section 5.4.5). Although Pearson's product-moment correlation coefficient has been used to assess reliability in some published studies such as Donovan et al (2008), I decided it would not be suitable, since the correlation would be $r = 1.00$ if scores on the second rating were all exactly half of scores on the first rating. Dr Clark also advised against the use of Pearson's correlation in this context. I chose a random effects rather than a mixed effects intraclass correlation,

since I wished to generalise conclusions beyond these particular ratings (Shrout and Fleiss, 1979).

In order to assess the relative contributions of factors including cognitive status on communicative effectiveness and participation, I constructed two backwards stepwise multiple regression models. One regressed against CES score and the other against CPIB10 T score. A significant advantage of backwards stepwise models in exploratory analyses with moderate sample size is that the number of predictors is reduced as the model is iterated, which increases statistical power. I originally included HADS, MoCA, LEDD, educational status, age, employment category, gender and disease duration as predictors. I ran models in an iterative manner. On each iteration, I removed the predictor with the lowest F statistic. I iterated the model until all remaining predictors had a p value of ≤ 0.1 . I then reported $p < 0.05$ as significant and $p < 0.1$ as marginally significant results.

In order to assess which sub-domains of MoCA may be most relevant for communicative effectiveness and participation, I constructed two backwards stepwise multiple regression models. One regressed against CPIB10 T score and the other against CES score. All MoCA sub-domains were initially included: visuospatial/executive, naming, attention, language, abstraction, delayed recall and orientation. I included other factors that were retained at $p < 0.1$ in the analyses described above (see sections 6.5.4 and 6.5.5). I ran the model in an iterative manner. On each iteration, I removed the predictor with the lowest F statistic. I iterated the model until all remaining predictors had a p value of ≤ 0.1 . I then reported $p < 0.05$ as significant and $p < 0.1$ as marginally significant results.

Since speech analyses were only performed on a subset of participants, I used separate models to assess the relationship between measures of intelligibility and communication from those presented above. I constructed two backwards stepwise multiple regression models. One regressed against CES score and the other against CPIB10 T score. I originally included read intelligibility and conversational intelligibility in addition to the predictors retained at $p < 0.1$ in the analyses above (see sections 6.5.4 and 6.5.5) as independent variables. These were HADS, MoCA and LEDD. I ran the models in an iterative manner. On each iteration, I removed the predictor with the lowest F statistic. I iterated the model until all remaining predictors had a p value of ≤ 0.1 . I then reported $p < 0.05$ as significant and $p < 0.1$ as marginally significant results.

6.5 Results

6.5.1 CPIB score profiles

Table 21: Score profiles for Communicative Participation Item Bank

	Overall	Samples		
		Speech	QCA CPIB	QCA Experiences
Not at all	11 (24%)	5 (25%)	6 (24%)	7 (30%)
A little	24 (53%)	12 (60%)	15 (52%)	10 (43%)
Quite a bit	9 (20%)	2 (10%)	6 (21%)	5 (22%)
Very much	1 (2%)	1 (5%)	1 (3%)	1 (4%)

These profiles show that severely reduced communicative participation was rare in my study sample. However, around 75% had some degree of reduced communicative participation. Around half reported that their communicative participation was affected a little by PD. Around a fifth reported that it affected their communicative participation quite a bit. Proportions were similar across the different sub-samples used in my study.

6.5.2 Test-retest reliability and convergent validity of CPIB

Table 22: Inter-relationships between Communicative Participation Item Bank measures

	CPIB10 Summary	CPIB10 T	CPIB10 logit	CPIB46 summary
CPIB10 summary		$r_{45} = 0.989^{***}$	$r_{45} = 0.988^{***}$	$r_{45} = 0.986^{***}$
CPIB10 T	$r_{45} = 0.989^{***}$		$r_{45} = 0.999^{***}$	$r_{45} = 0.975^{***}$
CPIB10 logit	$r_{45} = 0.988^{***}$	$r_{45} = 0.999^{***}$		$r_{45} = 0.975^{***}$
CPIB46 summary	$r_{45} = 0.986^{***}$	$r_{45} = 0.975^{***}$	$r_{45} = 0.975^{***}$	

* = $p < 0.05$, ** = $p < 0.01$, *** = $p < 0.001$, ? = $0.05 < p < 0.1$.

Table 23: Score profiles for Communicative Participation Item Bank and Communicative Effectiveness Survey

	Score 1	Score 2	Overall
CPIB	53.03 (9.14)	53.00 (9.57)	52.97 (9.56)
CES			21.44 (5.07)

Table 24: Reliability and validity of Communicative Participation Item Bank

	Intraclass correlation	Pearson's correlation
Reliability	$r_{43}=0.85^{***}$	
Validity		$r_{45}=0.74^{***}$

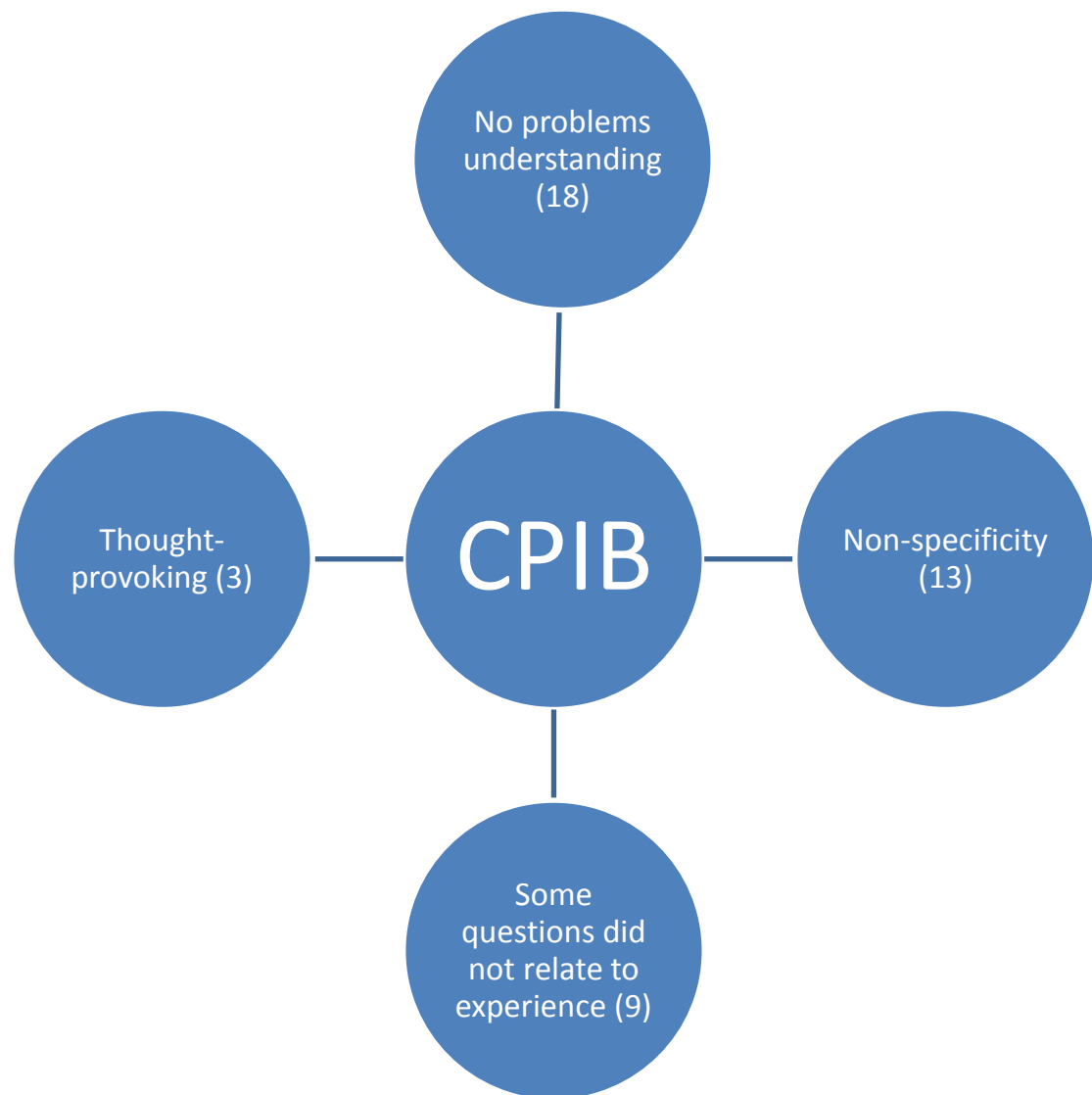
* = $p < 0.05$, ** = $p < 0.01$, *** = $p < 0.001$, ? = $0.05 < p < 0.1$.

My study provides evidence of high test-retest reliability and satisfactory convergent validity for CPIB, both statistically significant at $p < 0.001$. As I will discuss in chapter seven, communicative effectiveness and communicative participation are related but distinct concepts. The former relates to the Activity level of the ICF, while the latter relates to the Participation level. There is currently no gold standard measure for communicative participation. It is hoped that CPIB will become the gold standard. In the absence of a gold standard, I have used a related but conceptually distinct measure as a comparator scale for validity assessment. Therefore, it is to be expected that the concordance between CPIB and CES scores would be moderate.

6.5.3 QCA CPIB results

As discussed in chapter four, content analysis facilitates quantitative as well as qualitative analysis. Therefore, while I have performed the analysis using qualitative methodology, I will also discuss how many participants contributed to each theme. The following diagram shows the key themes I identified. The number of participants that contributed to each theme is indicated in brackets. Overall, twenty-nine participants contributed to QCA CPIB results.

Figure 4: Key themes in the views of people with Parkinson's disease on the Communicative Participation Item Bank



6.5.3.1 'No problems understanding'

Repeatedly, participants stated how they had no difficulty understanding CPIB. They had no difficulty with its purpose, format or phrasing. Most participants found no words to be problematic in transferring CPIB from an American cultural and linguistic context to a British context. This is illustrated by the following quotations:

"No problems with language or meaning" (Participant 39, male, age 61, moderate speech impairment).

"All questions were easy to answer" (Participant 49, male, age 85, mild speech impairment).

Several participants stated that CPIB was well structured, for example that "answers form several categories" (Participant 69, male, age 65, mild speech impairment).

The prevailing positive view of CPIB can be summarised effectively by this quotation:

"Can't knock it really" (Participant 79, male, age 66, moderate speech impairment)

6.5.3.2 'Non-specificity'

Some participants believed that the CPIB was not specific enough. This lack of specificity took a number of forms.

Some participants felt that it was difficult to interpret some questions since the communicative context was not clearly defined. This is exemplified by the quotations:

"Communicating in a small group of people- Do you come as a group? How many people are you visiting with? One of the crowd? What is the correct meaning?" (Participant 35, female, age 75, severe speech impairment).

"It depends who, for example, giving someone detailed information" (Participant 83, male, age 64, mild speech impairment).

Some respondents said that there was not always an appropriate answer for them, and that their answers were influenced by a range of factors apart from PD. This is exemplified by the following quotations:

"I think the answer to most of the questions will vary day to day" (Participant nine, male, age 82, moderate speech impairment).

“There wasn’t a box to tick for what I wanted to say a lot of the time, for example making a phone call to get important information- I just wouldn’t make the phone call; I would get someone else to do it for me” (Participant 47, male, age 65, moderate speech impairment).

“Deterioration could equally be caused by old age, deafness, drink, side effects of medication for example, not just Parkinson’s” (Participant 85, male, age 73, mild speech impairment).

Some participants thought that CPIB was too broad. This is exemplified by the following quotations:

“Some questions were repeated- the same but put in a different way” (Participant 71, female, age 72, mild speech impairment).

“That was horizon to horizon questions on communication, of which no doubt Parkinson’s could play a part” (Participant 85, male, age 74, mild speech impairment).

6.5.3.3 ‘Some questions did not relate to my experience’

Some respondents found that some questions in CPIB did not relate to their own every day or recent experience. This mainly appeared to be as a result of questions about activities that some participants could no longer perform as a result of their Parkinson’s. This is illustrated by the following quotations:

“The following questions were difficult to answer, as I have not experienced these situations: Communicating during an emergency and talking about an emotional issue with family or friends” (Participant 17, male, age 75, moderate speech impairment)

“Situations that I have just used my imagination either because I have never done them or only a long time ago: communicating when you are out and about in your community, negotiating and communicating during an emergency” (Participant 35, female, age 75, severe speech impairment).

Only one respondent mentioned a problematic Americanism as exemplified by the following quotation:

“I had difficulty with “visiting with others in a public place (e.g. park, restaurants, sports activity)”- visiting with is an Americanism” (Participant 35, female, age 75, severe speech impairment).

One respondent was “not at all convinced at the value” of the CPIB (Participant 85, male, age 73, mild speech impairment).

6.5.3.4 ‘Thought-provoking’

A few participants reported that CPIB had really made them think about aspects of their communication about which they had seldom thought. This is illustrated by the following quotations:

“Questions made me realize some things have changed, made me ask questions of myself”, “Good questions, specific things I may not normally think about in detail” (Participant 69, male, age 65, mild speech impairment).

6.5.4 Relationship between cognitive status and communicative effectiveness

Table 25: Relationship between cognitive status and communicative effectiveness

Predictor	F	P value	η^2
Model 1			
HADS	12.32	0.001	
Education	1.45	0.24	
LEDD	1.05	0.31	
MoCA	0.67	0.42	
Age	0.24	0.63	
Employment	0.18	0.68	
Gender	0.06	0.81	
Duration	0.00	1.00	
Model 2			
HADS	17.38	<0.001	
LEDD	2.47	0.13	
Education	1.15	0.29	
MoCA	0.44	0.51	
Employment	0.39	0.54	
Age	0.12	0.74	
Gender	0.06	0.80	
Model 3			
HADS	18.01	<0.001	
LEDD	2.49	0.12	
Education	1.21	0.28	
Employment	0.59	0.45	
MoCA	0.54	0.47	
Age	0.09	0.77	
Model 4			
HADS	18.46	<0.001	
LEDD	2.49	0.12	
Education	1.21	0.28	
MoCA	0.87	0.36	

Employment	0.67	0.42	
Model 5			
HADS	18.27	<0.001	
LEDD	2.55	0.12	
MoCA	0.96	0.33	
Education	0.64	0.43	
Model 6			
HADS	18.59	<0.001	
LEDD	2.21	0.15	
MoCA	1.46	0.23	
Final model			
HADS	20.18	<0.001	0.32
LEDD	3.72	0.06	0.06

The final model retained HADS as the only significant predictor of communicative effectiveness (CES) at $p < 0.05$. There was also a marginally significant result for LEDD at $p = 0.06$. Therefore, PwPD who were less depressed and anxious, and who took less medication, communicated more effectively. The LEDD finding should not be interpreted as meaning that dopaminergic medication impairs communication, but rather LEDD should be seen as a proxy for disease severity. Cognitive status as measuring by MoCA did not significantly predict communicative effectiveness.

6.5.5 Relationship between cognitive status and communicative participation

Table 26: Relationship between cognitive status and communicative participation

Predictor	F	P value	η^2
Model 1			
MoCA	5.33	0.03	
HADS	2.38	0.13	
Duration	2.09	0.16	
Employment	1.92	0.18	
Gender	1.04	0.32	
Age	0.86	0.36	
Education	0.31	0.58	
LEDD	0.02	0.89	
Model 2			
MoCA	7.46	0.01	
HADS	3.64	0.07	
Employment	2.75	0.11	
Gender	2.47	0.13	
Duration	2.13	0.15	
Age	0.71	0.41	
Education	0.09	0.77	
Model 3			
MoCA	7.98	<0.01	
Employment	4.05	0.05	
HADS	3.69	0.06	
Gender	2.65	0.11	
Duration	2.12	0.15	
Age	0.80	0.38	
Model 4			
MoCA	9.16	0.005	
Employment	3.55	0.07	
HADS	3.54	0.07	
Duration	2.73	0.11	
Gender	2.38	0.13	
Model 5			
MoCA	9.08	0.005	
HADS	2.97	0.09	
Duration	2.95	0.09	
Employment	1.96	0.17	
Model 6			
MoCA	8.46	0.006	
HADS	5.47	0.03	
Duration	2.83	>0.10	
Final model			
MoCA	8.99	0.005	0.15
HADS	8.73	0.005	0.15

The final model retained MoCA and HADS as significant predictors of communicative participation (CPIB). Therefore, PwPD who had greater cognitive impairment, and anxiety and depression had lower communicative participation. MoCA and HADS each explained 15% of the variance in CPIB score.

6.5.6 Relationships between MoCA sub-domains and communicative effectiveness

Table 27: Relationships between cognitive domains and communicative effectiveness

Predictor	F	P value	η^2
Model 1			
HADS	15.25	<0.001	
MoCA Naming	7.29	0.01	
MoCA Abstraction	6.09	0.02	
MoCA EVS	5.98	0.02	
MoCA Recall	2.38	0.13	
LEDD	1.92	0.18	
MoCA Orientation	1.81	0.19	
MoCA Attention	1.56	0.22	
MoCA Language	0.00	0.99	
Model 2			
HADS	15.74	<0.001	
MoCA Naming	8.52	<0.01	
MoCA Abstraction	6.67	0.01	
MoCA EVS	6.30	0.02	
MoCA Recall	2.56	0.12	
LEDD	2.05	0.16	
MoCA Attention	1.94	0.17	
MoCA Orientation	1.87	0.18	
Model 3			
HADS	14.51	0.001	
MoCA Naming	7.53	0.01	
MoCA Abstraction	4.89	0.03	
MoCA EVS	4.49	0.04	
MoCA Recall	3.73	0.06	
LEDD	3.03	0.09	
MoCA Attention	1.00	0.32	
Model 4			
HADS	13.73	0.001	
MoCA Naming	7.63	<0.01	
MoCA Recall	4.12	0.05	
MoCA Abstraction	4.10	0.05	
MoCA EVS	3.52	0.07	
LEDD	2.56	0.12	
Model 5			
HADS	15.94	<0.001	
MoCA Naming	5.51	0.02	
MoCA Abstraction	2.42	0.13	
MoCA Recall	2.21	0.15	
MoCA EVS	2.17	0.15	
Model 6			
HADS	13.54	0.001	
MoCA Naming	4.38	0.04	
MoCA Abstraction	2.72	0.11	
MoCA Recall	1.34	0.26	

Model 7			
HADS	14.23	0.001	
MoCA Naming	3.54	0.07	
MoCA Abstraction	2.18	0.15	
Final model			
HADS	14.69	<0.001	0.24
MoCA Naming	4.07	<0.05	0.07
EVS= Executive and visuospatial, Recall= Delayed recall			

Overall MoCA score did not significantly predict communicative effectiveness. However, this sub-domain model shows that MoCA naming score was a significant predictor of CES. PwPD who had greater naming ability were more effective in communication. MoCA attention and executive/ visuospatial sub-scores were eliminated relatively early in the model. This suggests that these aspects of cognition may not be particularly important for communicative effectiveness. However, MoCA is not a sufficiently comprehensive cognitive assessment to confirm this possibility.

6.5.7 Relationships between MoCA sub-domains and communicative participation

Table 28: Relationships between cognitive domains and communicative participation

Predictor	F	P value	η^2
Model 1			
HADS	11.31	0.002	
MoCA EVS	4.25	0.05	
MoCA Attention	2.49	0.12	
MoCA Orientation	1.24	0.27	
MoCA Language	0.24	0.63	
MoCA Abstraction	0.12	0.73	
MoCA Recall	0.04	0.84	
MoCA Naming	0.002	0.97	
Model 2			
HADS	12.51	0.001	
MoCA EVS	4.39	0.04	
MoCA Attention	2.56	0.12	
MoCA Orientation	1.28	0.26	
MoCA Language	0.28	0.60	
MoCA Abstraction	0.12	0.73	
MoCA Recall	0.05	0.82	
Model 3			
HADS	12.84	0.001	
MoCA EVS	4.48	0.04	
MoCA Attention	2.58	0.12	
MoCA Orientation	1.17	0.27	
MoCA Language	0.28	0.60	
MoCA Abstraction	0.13	0.72	
Model 4			
HADS	13.34	0.001	
MoCA EVS	4.45	0.04	
MoCA Attention	2.51	0.12	
MoCA Orientation	1.17	0.29	
MoCA Language	0.27	0.61	
Model 5			
HADS	14.75	<0.001	
MoCA EVS	4.28	<0.05	
MoCA Attention	3.61	0.07	
MoCA Orientation	1.25	0.27	
Final model			
HADS	14.20	0.001	0.23
MoCA EVS	3.22	0.08	0.05
MoCA Attention	3.05	0.09	0.05

EVS= Executive and visuospatial, Recall= Delayed recall

Overall MoCA score was a significant predictor of communicative participation, predicting 15% of CPIB score. This analysis assessed which sub-domains of MoCA contributed most to this effect. The executive/ visuospatial and attention sub-domains

were retained as marginally significant ($p < 0.1$) in the final model. Each predicted 5% of variance in CPIB score.

6.5.8 Relationships between speech impairment and communicative effectiveness

Table 29: Relationships between speech impairment and communicative effectiveness

Predictor	F	P value	η^2
Model 1			
Conversational intelligibility	1.28	0.28	
MoCA	0.92	0.36	
HADS	0.82	0.39	
Read intelligibility	0.01	0.92	
LEDD	0.00	0.98	
Model 2			
Conversational intelligibility	2.44	0.14	
HADS	1.35	0.27	
MoCA	0.73	0.41	
Read intelligibility	0.01	0.94	
Model 3			
Conversational intelligibility	6.23	0.03	
HADS	1.76	0.20	
MoCA	0.56	0.47	
Model 4			
Conversational intelligibility	9.71	0.01	
HADS	1.55	0.23	
Final model			
Conversational intelligibility	13.65	0.002	0.43

The final model retained only conversational sentence intelligibility as a significant predictor of communicative effectiveness (CES). It predicted 43% of variance in CES scores. Read sentence intelligibility did not significantly predict CES scores.

6.5.9 Relationships between speech impairment and communicative participation

Table 30: Relationships between speech impairment and communicative participation

Predictor	F	P value	η^2
Model 1			
MoCA	8.61	0.02	
LEDD	0.41	0.54	
HADS	0.35	0.58	
Conversational intelligibility	0.20	0.67	
Read intelligibility	0.03	0.87	
Model 2			
MoCA	2.82	0.12	
Conversational intelligibility	1.55	0.24	
LEDD	0.39	0.55	
HADS	0.10	0.76	
Model 3			
MoCA	3.27	0.09	
Conversational intelligibility	1.58	0.23	
LEDD	0.52	0.48	
Final model			
MoCA	5.32	0.04	0.20
Conversational intelligibility	4.96	0.04	0.19

The final model retained MoCA and conversational sentence intelligibility as significant predictors of communicative participation (CPIB). MoCA explained 20% of the variance in CPIB score, whereas conversational intelligibility explained 19%. Read sentence intelligibility was not a significant predictor of CPIB.

6.5.10 QCA experiences of speech and communicative impairment

The following diagram shows the key themes I identified. The number of participants that contributed to each theme is indicated in brackets. Overall, twenty-three participants contributed to QCA results about experience of speech and communicative impairment (QCA communication results). The multi-faceted aspects of speech and communication cannot be reduced to a single overarching theme.

Figure 5: Key themes in the experiences of people with Parkinson's disease of speech and communicative impairments



6.5.5.1 Physical speech impairment

Many respondents reported physical difficulties with speech production. A lack of voice projection was a frequent concern. This is exemplified by the following quotation:

‘Volume is essential- but is not there’ (Participant 73, male, age 93, moderate speech impairment).

Several respondents expressed concern about the sound of their voice, as exemplified by the following quotations:

‘It tends to have a slightly creaky edge to it’ (Participant 83, male, age 64, mild speech impairment).

‘My voice can come across high pitch, like a girl’ (Participant 79, male, age 66, moderate speech impairment).

A few participants reported difficulties with articulation. One reported ‘problems with tongue control’ (Participant 59, female, age 76, mild speech impairment). Another said that he wasn’t ‘quite as articulate as I used to be’ (Participant 81, male, age 61, mild speech impairment). Another said that ‘sometimes I can’t get a sentence out- a few times a week’ (Participant 83, male, age 93, moderate speech impairment).

Several participants reported that they had reduced speech rate. This is illustrated by the following quotation:

‘slower in speaking’ (Participant 71, female, age 72, mild speech impairment).

Two participants described how increased salivation affected their speech. This is exemplified by the following quotation:

‘noticed increased salivation may stop me starting or continuing a conversation’ (Participant 69, male, age 65, mild speech impairment).

6.5.5.2 Social psychological factors

Many respondents said that they had become less outgoing since the onset of their PD. This is exemplified by the following quotations:

‘I want to communicate less’ (Participant 67, male, age 68, mild speech impairment).

‘I avoid joining conversations’ (Participant 75, male, age 71, mild speech impairment).

Self-consciousness and anxiety about speech and communication were common concerns. This is illustrated by the following quotations:

'I am aware of my speech, this impacts on my speech' (Participant 69, male, age 65, mild speech impairment).

'There is a feedback loop with anxiety- more anxiety, more mistakes, more anxiety' (Participant 83, male, age 64, mild speech impairment).

As exemplified by the following quotation, one respondent demonstrated the influence of state of mind on communicative participation:

'It gets difficult if I'm upset' (Participant 61, female, age 65, moderate speech impairment).

Some participants felt ignored in group communication. Sometimes, this was due to difficulty breaking into conversations. In other cases, it was the result of speaking too quietly and not being noticed. This is illustrated by the following quotation:

'Breaking into a conversation with a group is very hard- they've moved on by the time I break in'. I feel left out, people don't involve me' (Participant 73, male, age 93, moderate speech impairment).

Many respondents described how their communicative participation was influenced by their personality and previous life experiences. One respondent, who had severe speech impairment, said that communicating in 'noise is not a problem', because he 'used to go to clubs often' (Participant 53, male, age 70, severe speech impairment).

The following two quotations demonstrate how respondents' communicative participation was influenced by how outgoing their personality was:

'I have always been quiet and not so outgoing' (Participant 79, male, age 66, moderate speech impairment)

'I have a very positive outlook' (Participant 87, female, age 63, mild speech impairment).

6.5.5.3 Communicative context

Repeatedly, respondents said that the detailed communicative context played a key role in determining their communicative effectiveness and participation. Contextual factors can be sub-divided into 'who', 'what', 'where' and 'when'.

Several respondents said that they had much more difficulty communicating with people they didn't know, as illustrated in the following quotation:

'With people I know less it's worse- it's OK with friends and family ... but with strangers my speech is affected' (Participant 51, male, age 64, mild speech impairment)

Several people said that it was easier to communicate one-to-one rather than in groups, for example saying 'One to one is best. Groups are difficult- I could be ignored altogether' (Participant 73, male, age 93, moderate speech impairment). However, one person said that 'speech is best when surrounded by familiar people' (Participant 53, male, age 70, severe speech impairment). This may relate to personality as discussed in section 6.5.5.2.

Several respondents reported an effect of the topic on their communication, as exemplified by the following quotation:

'If it's a topic I know something about or feel strongly about I can converse reasonably well. If I don't know anything about it or am bored with it, there would be a great deal of trouble and there would be large gaps between sentences' (Participant 81, male, age 61, mild speech impairment).

The physical location where conversations took place was important for many respondents. The majority found it difficult to communicate in noisy locations, such as while travelling in a car or in a busy room. This is exemplified by the following quotation:

'It is difficult to speak in a crowded room, such as the residents' hall, it is hard to make myself heard' (Participant 71, female, age 72, mild speech impairment).

Two participants said that they had more difficulty communicating in the evening, as illustrated by the following quotation:

'My wife says I tend to mumble in the evening' (Participant 85, male, age 73, mild speech impairment).

One participant said that while he found it difficult to speak, he was still 'able to sing' (Participant 53, male, age 70, severe speech impairment). This communication modality effect could in part relate to social experience, as well as to potential physical factors.

6.5.5.4 Communicative effectiveness

Some participants found that, on the whole, they could communicate effectively. This is illustrated by the following quotations:

'It's not really interfered with communicative situations' (Participant 63, female, age 68, mild speech impairment)

'My communication is usually OK' (Participant 79, male, age 66, moderate speech impairment).

On the other hand, some participants described how their overall communication had become markedly less effective. This is illustrated by the following quotations:

'My communication has deteriorated' (Participant 67, male, age 68, mild speech impairment)

'I sometimes can't achieve what I want to achieve with the simplest things when I'm at home' (Participant 81, male, age 61, mild speech impairment).

One participant said that 'facial expression is a problem- not much expression' (Participant 73, male, age 93, moderate speech impairment).

6.5.5.5 Cognition

Some participants stated that cognitive impairment affected their communication. The most frequently cited cognitive consequence was word finding problems. This is illustrated by the following quotations:

'Forgetfulness is the problem' (Participant 47, male, age 65, moderate speech impairment)

'I get words muddled up sometimes' (Participant 67, male, age 68, mild speech impairment)

'Mental and physical factors- I really believe that the communication side could have two separate sources' (Participant 85, male, age 73, mild speech impairment).

'Breaking into conversation with a group is very hard- they've moved on by the time I break in' (Participant 73, male, age 93, moderate speech impairment).

6.5.5.6 Effort

Commonly, respondents said that speech production was effortful and made them tired. Sometimes, they forgot to use strategies that made their communication more effective. This is illustrated by the following quotations:

'If I'm aware, I can speak up but sometimes forget' (Participant 65, male, age 55, mild speech impairment)

'I sometimes have to emphasise' (Participant 79, male, age 66, moderate speech impairment).

One participant showed how much effort it involved to retain sufficient social participation, as illustrated by the following quotation:

‘I try hard to keep active, I still sing but not as much as before’ (Participant 63, female, age 68, mild speech impairment).

6.5.5.7 Parkinson’s pathway

Some participants discussed their speech and communicative impairments in the context of the wider PD pathway. While one participant felt that medication was helpful for speech, three participants said that medication side effects had a detrimental effect on speech. This is illustrated by the following quotations:

‘It’s the early stage, medication is helping’ (Participant 57, female, age 48, mild speech impairment)

‘Dyskinesia affects speech’ (Participant 51, male, age 64, mild speech impairment)

‘A little of a dry throat’ (Participant 65, male, age 55, mild speech impairment)

One respondent believed that speech impairment was among the earliest signs of his PD, whereas another respondent believed that his speech difficulties will get much worse, but were not currently a major concern. This is illustrated by the following quotations:

‘Speech was one of the first symptoms’ (Participant 75, male, age 71, mild speech impairment)

‘I think in terms of my overall Parkinson’s, communication and speech is (sic) the least of my worries at the moment’ (Participant 85, male, age 73, mild speech impairment).

6.6 Overview of results

All CPIB measures were very highly inter-correlated, with the result that I only used CPIB10 T scores in my analyses. Satisfactory validity, reliability and participant acceptability were found for CPIB. Total MoCA score significantly predicted CPIB score. MoCA attention and executive/ visuo-spatial sub-domain scores significantly predicted CPIB score. Total MoCA score did not significantly predict CES score. However, a significant association was found between MoCA naming sub-domain score and CES score. Results of QCA communication analyses show that psychosocial and cognitive factors, in addition to physical speech impairment, were important aspects of

communicative difficulties. Intelligibility in conversational sentences significantly predicted CPIB and CES. However, the amount of variance predicted was modest. Intelligibility in read sentences did not significantly predict either communicative outcome.

6.7 Summary

This chapter started by providing the rationale for my validation of the CPIB in my study population and describing how this was performed. It then explained how I used QCA to explore the acceptability of CPIB to participants and their experiences of speech and communicative impairments. It described and justified my statistical analysis methods. In conclusion, it presented my results about communication in Parkinson's disease. The following chapter synthesises my findings, discusses them in the context of extant knowledge and suggests future research directions. It concludes by evaluating my study in the context of the criteria for the award of a doctorate.

Chapter 7: Discussion

7.1 Summary of findings

My thesis investigated relationships between cognitive status, speech impairment, and communicative participation in PD.

Satisfactory reliability was demonstrated for phonetic analysis. PwPD, of whom 70% were judged to have mild speech impairment, were shown to be impaired on a range of sentence-level acoustic parameters in read and emotional sentences. Cognitive status predicted some sentence-level acoustic speech characteristics in read and emotional sentences, but no effect was found for conversational sentences.

Listeners were less accurate for PwPD for each of read, conversational and emotional sentences compared to CPs. The cognitive status of speakers only associated with listener accuracy in emotional, not read or conversational sentences. In read sentences, listeners were more accurate in transcribing the speech of PwPD who spoke more loudly and paused less. No significant associations between acoustic characteristics and listener accuracy were identified for conversational or emotional sentences.

Satisfactory convergent validity, test-retest reliability and participant acceptability were found for CPIB. Total MoCA cognitive score significantly predicted communicative participation (CPIB) but not communicative participation (CES). While attention and executive/visuo-spatial function were the MoCA sub-domains that significantly predicted CPIB, it was the MoCA naming sub-domain that significantly predicted CES. Read sentence intelligibility did not predict CPIB or CES. Conversational sentence intelligibility had a modest relationship with communicative outcomes, predicting 19% of the variance in CPIB scores and 43% of the variance in CES scores. QCA communication results provided evidence that speech and communication difficulties in Parkinson's disease result from a complex interplay of physical, cognitive and psychosocial factors. My study demonstrated that reduced communicative participation was common even in people with Parkinson's disease who predominantly had mild objective speech impairment.

7.2 Evaluation

7.2.1 Strengths

My study has many particular strengths compared with the extant body of literature. In the discussion of my systematic review of extant knowledge regarding the

relationship between cognitive status, and speech and communicative impairments in PD (see chapter 3), I said that further work was needed, especially with regard to communicative participation. My study addressed this challenge to find a cognitive assessment that is sufficiently sensitive to mild cognitive impairment in PD and a means of measuring communicative participation that probes directly the impact of PD on participation in a range of everyday communicative situations.

My study provides a same-sample overview of the pathway from cognitive (and motor) impairments, through impaired speech characteristics and intelligibility, to reduced communicative activity and participation. It covers all three ICF domains and offers separation of participation from activity. This offers a unique perspective on the entire pathway. Moreover, it offers a rare British perspective on the speech acoustics of PwPD.

My study uses a multimethod research paradigm to provide thorough topic coverage and self-validate using triangulation. The use of self-report communication measures CES and CPIB offers the participants' perspective on their own communication, rather than relying on observer-rated measures which report communication from a relative's or clinician's perspective. My study extended its portrayal of the participant perspective through the use of qualitative content analysis. I performed two qualitative content analyses (QCA), each making their own unique contribution. The CPIB QCA extended my classical validation of CPIB in a UK PD context, by adding a perspective on the acceptability of CPIB to participants. For an assessment scale to be successful, it must be acceptable to its target client group.

Unlike many other studies, I included semi-naturalistic conversational speech in addition to read speech. As discussed in 7.2.2, observed speech is never totally natural. Semi-naturalistic conversational speech is much more similar to everyday communication than reading sentence lists. However, due to challenges in analysing the speech acoustics of spontaneous speech due to non-standard content, the majority of studies investigating the acoustic speech characteristics of PwPD exclusively used standardised read sentence lists or passages.

PwPD in my study had a fairly broad and representative range of demographic and clinical characteristics. Although the study was run from Norwich and all participants lived in Norfolk or Suffolk, participants came from a wide range of localities across the UK and consequently had a wide range of UK accents. This increases generalisability of results and safeguards against the suggestion that the study's findings could have been an artefact of the local accent characteristics of the region where the study was based. For an excellent exposition of the Norwich accent and dialect, consult Trudgill (1974,

1988). Limited generalisability is a frequent limitation of single-centre speech studies, and one that my study did not encounter. With the exception of gender (see section 7.2.2), the PD and CP purposive speech samples were well-matched for demographic characteristics. This is an advantage of my study, since it means it is less likely that observed group differences were in fact a result of a confounding variable. The close equivalence in sample demographics also meant it was not necessary to co-vary for a range of demographic characteristics in my speech analyses. This in turn increased my statistical power.

There is a need for high quality studies of speech and communication in PD. My study has certain limitations (see section 7.2.2). However, as outlined above, my study has some particular strengths. As discussed in section 7.2.2, these contrast with many extant studies, particularly those investigating acoustic speech characteristics. As discussed in section 7.5, I have presented my findings at the 17th International Congress of Parkinson's Disease and Movement Disorders organised by MDS, and will submit my results papers for consideration by appropriate journals.

7.2.2 Addressing potential limitations

All research studies involving human participants have limitations due to the unpredictability and variability of human behaviour (Cziko, 1989, Willerman, 1979). This means that while a plan is essential, it is equally essential to be flexible enough to modify the study approach slightly in response to participant characteristics and needs.

PhD studies are constrained by limited human, financial and temporal resources. Although a longitudinal design would have offered a clearer interpretation of causal relations, there is insufficient time within a PhD to conduct a study with a follow-up period longer than six months. The relative benefit of such a short period of follow-up over and above a cross-sectional design is highly questionable. Moreover, due to attrition bias, longitudinal decisions require a larger initial sample size to produce the same sample size at follow-up that would be achieved using a cross-sectional design. Therefore, a cross-sectional design was most appropriate for my study.

Additionally, in PhD studies, a short recruitment period and a lack of financial resources to run multiple research sites or have other research staff, impose restrictions on sample size. This prevented the use of principal components analysis, which could have provided a useful conceptual grouping of acoustic variables prior to regressing against listener outcomes. Moreover, phonetic analysis is highly resource intensive. Since I performed all the phonetic analysis, it was only possible to perform phonetic analysis on

a subset of participants. Additionally, as discussed in section 5.4.4, there were a small number of phonetic measures which I did not have time to complete. Performing phonetic analysis on conversational speech samples is intrinsically considerably more challenging than analysing read sentences, due to non-standard content, which introduces a wide range of potential sources of variance.

However, sample size is a frequent challenge for studies of speech and communication, not solely those conducted in the context of a PhD. Since phonetic analysis is resource intensive in terms of parameter refinement and conduct of analyses, sample sizes are often restricted, unless a large number of skilled analysts are available. As indication of the magnitude of the challenges faced, phonetic studies cited in chapter two of this thesis included on average fewer than fifteen PwPD. Listener studies using standardised read sentences also face sample size limitations, due to the potential of stimulus learning effects (see section 5.5.3.1). In my systematic review of extant knowledge about relationships between cognitive status, and speech and communicative impairments in PD, included studies recruited a median of twenty PwPD. In the context of studies in other aspects of PD, this is not particularly large.

Limited sample size makes it difficult for studies in this field to have satisfactory statistical power for fine-grained well-controlled statistical analyses. For practical and design reasons outlined earlier in this thesis, I could only include twenty PwPD and twenty CPs in my speech analyses. This means that my sample size for this aspect of my project was above average for the field, but smaller than ideal. Therefore, I adopted a two-tier approach to sample size. For the communicative analyses, in which the above restrictions did not apply, I used a sample size of forty-five PwPD, in order to provide greater statistical power for the intended analyses and to increase generalisability. My sample size for communicative analyses was larger than all communicative studies in my systematic review, with the exception of Miller et al (2008, 2011).

Although this was partly redressed by purposive sampling for speech measures, there was a sampling bias towards PwPD who had mild speech impairment. The underrepresentation of those with moderate-to-severe speech impairment may relate to increased self-consciousness of people with moderate-to-severe speech impairment about being recorded. Anecdotal evidence for this suggestion comes from the receipt of several responses to study invitations, saying that while the person was interested in the project and supportive of research, he or she did not feel able to participate in this particular study, as a result of self-consciousness about either the topics of speech and communication or about being recorded.

Although the inclusion criteria for my study (see section 4.4.2) exclude people with dementia, identification of dementia prior to invitation relied on clinic records. Since PwPD were invited by clinic staff two weeks prior to attending clinic, it is possible that some may not have been assessed for a while. Therefore, it is possible that some people who had no diagnosis of dementia could have declined cognitively since their previous appointment, to an extent where they may have had mild dementia at the point of invitation. However, my study investigated the impact of a wide range of cognitive status on speech and communicative outcomes, rather than the putative concept of mild cognitive impairment as strictly defined. On no occasion did I visit a potential participant and subsequently find that he or she was incapable to consent.

Any misunderstandings about the nature of the study were minor and resulted from lack of prior experience of the topic or research, rather than dementia. Where misunderstandings arose, I provided clarification before seeking consent. On one occasion, following telephone discussion between the carer and me, it was decided that a study appointment should not be made for one interested potential participant, due to concerns by the carer and a consultant physician about dementia. This situation arose because invitations were sent out two weeks before the patient's next clinical appointment. This means that if the PwPD or a relative had any significant concerns regarding dementia, they could discuss them with the clinical care team prior to deciding whether to participate in my research study. Therefore, any dementia amongst the included participants would have been mild.

MoCA scores provide an indication of how many participants in my study may have had mild dementia. Nasreddine et al (2005) report MoCA scores between 11 and 21 for people with Alzheimer's disease, with a mean of 16 and standard deviation of five. Fifteen of my participants had a MoCA score of ≤ 21 . However, only three had a MoCA score ≤ 16 . Therefore, it is probable that a small number of my participants had mild dementia. Due to the nature of the investigation, the impact of this on the interpretation of my results is low. My inclusion criteria did not exclude intact cognitive status, since I wanted to be able to compare the impact of a range of cognitive status. Nine of my participants showed evidence of intact cognitive status according to MoCA. MoCA score was not available for one of my 45 participants. Therefore, with a small number of exceptions, it appears that my study recruited its intended sample.

Due to the ethical requirement to use university members as assessors, listeners were not demographically similar to speakers in intelligibility and emotional conveyance assessment. University members are younger and more highly educated than the general population. In addition, since my study only had the funds to offer a modest prize draw,

most assessors came from schools of study that were to some extent related to the topic of my study. Since the majority of students in these schools are female, and men are known to be harder to recruit into studies, 88% of the assessors in my study were female. This contrasts with 35% of PwPD and 65% of CPs in the speech analysis sample. However, older people converse with younger people, men with women and the more educated with the less educated. Therefore, it is unclear whether these demographic differences between speakers and listeners would have had any impact on the results of listener assessment.

It would have been interesting to have included an age-matched assessor group. However, this would have involved recruiting assessors from the community. I was advised that, for ethical reasons, university members should be used as assessors since pre-existing contractual arrangements provide additional safeguards should assessors recognise any speakers. The only way it could have been possible to use an age-matched community-based assessor sample would have been to recruit assessors from a different region of England. This would have posed considerable challenges in terms of advertising, finding suitable venues to conduct the assessment sessions, cost and appropriate transport of personal data.

Although the conversations included in my study can be called semi-naturalistic, it is not possible to obtain fully natural speech from people who know they are being observed. This is called the Observer's Paradox (Cukor-Avila, 2000, Labov, 2006, Labov, 1966) and is a challenge for all social psychological and sociolinguistic investigations. Under current UK law and ethical standards, all studies seeking to obtain naturalistic behaviour will face this limitation. To partly mitigate this limitation, any conversations that appeared significantly unnatural were excluded from analysis by purposive sampling (see section 5.4.2).

MoCA, HADS, CES and CPIB were not measured in the CP group. CPIB is not suitable for comparing the communicative participation of a patient group with a control group because it asks how much a person's communicative participation has changed since having a condition. It was decided that administering MoCA, HADS and CES to CPs would make the data collection session excessively long. The absence of these baseline measures for CPs meant that I could not control for HADS or MoCA in group comparisons of speech acoustics. Additionally, intact cognitive status and communicative participation in CPs had to be inferred. The existence of impaired cognitive status and communicative participation in PwPD in my study had to be inferred from normative data and extant knowledge, rather than through group comparison within my sample. With

regard to communicative participation, QCA communication results addressed this limitation.

7.3 Contextualisation

Previous investigations of the effect of PD on the acoustic speech characteristics of non-emotional speech, conducted in the context of non-British varieties of English or other languages, have seldom investigated the potential role of cognitive, in addition to motor speech factors. The majority of PwPD who participated in my study had mild speech impairment. Probably as a result of the overall mild speech impairment in my sample, previously published group differences were not replicated for certain acoustic characteristics.

In the read speech task, there was evidence that PwPD had significantly reduced speech intensity but no group difference in intensity decay. Women with PD had significantly lower MNF_0 , with a marginally significant result for increased MNF_0 for men. There was a marginally significant result for reduced SDF_0 for women, with no effect for men. These pitch-related findings represent a reduction in normal gender differences. Men with PD had significantly increased speech rate relative to gender-matched controls, whereas the effect was in the opposite direction for women. There was evidence that PwPD had a higher total pause time, with a marginally significant result for higher within-word pause time. No group differences were found with regard to iteration, FCR, jitter, HNR or consonantal measures. There was a marginally significant result for higher shimmer for CPs in /i/ and /u/ vowels.

In the conversational speech task, I found no evidence that PwPD spoke consistently more quietly. There was a marginally significant result for men with PD to have higher adjusted acceleration, although statistical significance was not reached. Women with PD were shown to have significantly increased iteration and within-word iteration, while men had decreased within-word iteration. No other group differences were found for conversation speech.

In my read sentence task, I provided further evidence for the widely attested (see section 2.4.2.2) reduction in loudness associated with PD. This phenomenon was also frequently cited in my QCA communication analysis. The absence of a significant group effect in loudness in conversational speech may relate to greater variability as a result of non-standard content. Pitch effects varied markedly as a function of gender and are discussed below. Unlike studies discussed in section 2.4.2.3, I found no substantive evidence of phoneme-level articulatory speech impairments in PD. This is likely to be

predominantly a consequence of the mild speech impairment characteristic of my sample. However, as discussed below, I did not replicate the commonly attested finding of voicing impairments associated with early speech impairment. I only found significant group differences in pause and iteration in the conversational task, potentially as a result of planning spontaneous speech content. Dysfluency has been attested in previous work (Goberman and Blomgren, 2003, Goberman et al., 2010, Benke et al., 2000) (see section 2.4.2.4).

Previous studies tended to analyse across gender. Gender effects found in my study suggest that this approach may have obfuscated important differential effects of gender and contributed to equivocal findings. For example (see section 2.4.2.4), previous studies have found increased, reduced and unaltered speech rate in PwPD. My finding that read speech rate was increased for men and decreased for women with PD suggests that these differences may have resulted from sample characteristics, including gender. However, my sample contained a relatively small number of people of each gender and gender was not balanced across groups. A relatively small number of studies have investigated gender effects with regard to voice and pitch phenomena.

I did not replicate the previous finding of increased jitter for men with PD (Hertrich et al., 1996, Rahn et al., 2007, Jiménez-Jiménez et al., 1997). Unlike Hertrich et al (1996), I found no evidence of reduced jitter and shimmer for women with PD. As discussed below, voice impairments were not prevalent in my sample. In the read speech task, I found evidence to support the findings of Holmes et al (2000) and Gamboa et al (1997) regarding increased MNF_0 for men with PD and Holmes et al (2000)'s finding that women with PD had reduced SDF_0 . My finding regarding increased MNF_0 for men was only marginally significant, probably due to a sample with milder speech impairment than the previous studies.

Due to difficulty obtaining naturalistic conversational data in research conditions and the challenge for phonetic analysis posed by non-standard content, conversational speech has seldom been investigated in PD. Only one study could be identified that sought to compare 'conversational' with 'clear' speech (Goberman and Elmer, 2005). One difficulty in the interpretation of speech results from studies using standardised read speech is that people read very differently from how they speak in normal conversation. This phenomenon was also demonstrated in my study. The use of monologues in studies is also problematic. Except for when delivering a lecture, the vast majority of natural human speech occurs in the context of conversational interaction. Therefore, monologues are unnatural and may not offer any significant advantages over the use of read speech. Moreover, they are associated with the disadvantage of non-standard content.

Goberman and Elmer (2005) compared ‘conversational’ and ‘clear’ speech within a sample of PwPD. No comparison with controls was made, so it is difficult to interpret what may constitute a speech impairment. Although descriptive data are available, my study did not explicitly compare read and conversational speech, but rather assessed group differences and cognitive effects in each separately. I was then able to draw conclusions about what phenomena occurred in read and/or conversational speech. Goberman and Elmer (2005) found reduced speech rate and increased MNF_0 and SDF_0 in ‘clear’ compared to ‘conversational speech’. However, the tasks were not comparable to my study. There were three tasks (/hVd/ sequences, a read passage and a monologue) each performed in two conditions (‘clear’ and ‘conversational’). The ‘conversational’ condition did not examine conversational speech as it was defined in this thesis, that is to say spontaneous speech produced in the context of inter-personal interaction.

Supporting the results of previous studies (see section 2.4.2.6), I found that PwPD in my study were less intelligible than CPs. It demonstrated that significantly reduced intelligibility was still present in a sample with predominantly mild speech impairment.

No study has provided a comprehensive characterisation of the relationships between acoustic speech characteristics and intelligibility in PD. Phonetic methods are resource-demanding, which restricts sample size. This, in turn, makes it difficult to assess a wide array of predictors simultaneously, while still maintaining reasonable statistical power. For this reason, I only assessed the impact on intelligibility of speech characteristics, for which a significant difference between PwPD and CPs had been obtained. This also ensured that I was characterising the impact of impaired speech acoustics on intelligibility, rather than speech variation within normal parameters. I also used a more comprehensive list of candidate parameters than previous investigations.

I found that PwPD who spoke more loudly and paused less were more intelligible for read speech sentences. Due to increased variability associated with non-standard content, I did not find any reliable associations between acoustic measures and intelligibility for conversational speech sentences. An association between loudness and intelligibility has been shown by previous studies (Neel, 2009, Tjaden and Wilding, 2004). However, these studies assessed the impact of asking people to speak more loudly, whereas I investigated the impact of naturally-occurring variation. My study suggests a role for pause, which to my knowledge, has not been found in any previous studies.

Second formant slope (Weismer et al., 2001, Tjaden and Wilding, 2004), vowel space area (Weismer et al., 2001) and fricative spectral mean (Tjaden and Wilding, 2004) have also been shown to significantly associate with intelligibility. I did not use these

exact measures. However, I did not find any associations between phoneme-level speech characteristics and intelligibility. This may relate to sample characteristics or the methods used. My study provided an overview of the relationship between speech acoustics and intelligibility in PD, using a wide range of candidate items, filtered through a test of group difference. It provided further evidence for the importance of loudness and provided novel evidence for a potential role of pause. No evidence was found to support the suggested role of vowel and consonant characteristics.

Some differences in the findings discussed above may result from methodological differences, especially regarding listener assessment. Whereas my study used an objective transcription task, both Weismer et al (2001) and Tjaden and Wilding (2004) used subjective intelligibility ratings. The former used a modulus of 100, while the latter allowed assessors to define their own scale. It is possible that the objective transcription task used in my study could provide a more accurate estimate of the successful conveyance of linguistic meaning from speaker to listener, as opposed to listener impressions of the speech clarity.

My systematic review (see chapter 3) identified only one study that investigated the relationship between cognitive status and acoustic speech characteristics assessed in a non-emotional context (Alpert et al., 1990). This study was assessed as being at high risk of bias. It measured cognitive status using a composite dementia scale that comprised the MMSE, the intellectual impairment subscale of UPDRS (Fahn et al., 1987) and two cognitive items from the Sandoz Clinical Examination- Geriatric (Shader et al., 1974). It found that the composite dementia scale was significantly negatively associated with the frequency of internal pauses, and positively associated with mean internal pause length. Therefore, PwPD who had more cognitive impairment paused less and these pauses were of shorter duration.

Alpert et al (1990) defined internal pauses as pauses within a speaking turn, so this measure corresponds more closely to my overall percentage pause time, rather than my within-word pause time measure. I have avoided the use of the term 'internal' to refer to the within-word pause measure in my study since it can relate to pause either within a specified linguistic unit or within a speaking turn.

I shall now discuss the results of my read sentence results with regards to cognitive status. I found that men with PD who had more intact cognitive status spoke more loudly, whereas the opposite effect was found for women. PwPD who had more intact cognitive status spoke with higher pitch. Men with more intact cognitive status had increased pitch variability, whereas the opposite effect was found for women. Men with

PD who had more intact cognitive status had higher HNR, which reached statistical significance for /i/ and /a/ vowels. No effect was found for females. No significant associations between cognitive status and acoustic speech characteristics were found for any other read speech parameters or for conversational sentences.

Mine is the first study, to my knowledge, that provided a thorough characterisation of relationships between cognitive status and a range of acoustic speech parameters of the speech of PwPD in a non-emotional context. The absence of significant associations in the conversational speech task may result from the increased variability inherent in tasks using non-standardised speech tasks. In light of the relatively small sample size of my speech analyses and the disagreement between read and conversational task results, my study cannot offer definitive evidence that cognitive status is an important contributing factor to acoustic speech characteristics in PD. It is able to suggest that cognitive status may have a role to play and is worthy of further investigation.

However, since significant associations between cognitive status and acoustic speech characteristics were only found in the read rather than the conversational task, it is possible that these cognitive effects could have resulted from participants having to focus more on the less natural read speech task. Ho et al (2002) provided evidence of an effect on the speech volume and timing of PwPD as a result of performing a concurrent motor task that occupied cognitive resources. It is possible that differential effects of cognitive status on the speech of men and women may relate to cognitive differences between the genders (Fisher, 1999, Halpern, 2000, Ren et al., 2009).

My systematic review (see chapter 3) identified only one study that investigated the association between cognitive status and intelligibility (Miller et al., 2007). It had a large sample size and was assessed as being at low risk of bias. This study found a significant association between MMSE score and listener-rated intelligibility. However, I did not find any evidence of a significant association between cognitive status and read or conversational sentence intelligibility. Despite the smaller sample size in my study, it does not appear that this could fully explain the lack of association, since p values were > 0.2 for both outcomes. However, Miller et al's (2007) study used word lists rather than read sentences or spontaneous as the speech material for listener-rated intelligibility assessment. Word lists are less representative of natural conversation than read sentences, which in turn are less representative than spontaneous speech. It is possible that the difference in findings between this study and mine is a consequence of different speech materials. Above, I discussed the potential of task-related cognitive load effects in relation to acoustic speech characteristics. With regard to intelligibility, it is again possible that the very unnatural word list task in Miller et al's (2007) study could have resulted in

an additional cognitive load, thereby bringing about an association between cognitive status and intelligibility. No such association was demonstrated in my study, although there was potential evidence of cognitive load effects with regard to the acoustic speech characteristics of read sentences. It is possible that such effects in my study were not of sufficient magnitude to affect intelligibility. On the other hand, it remains possible that there could be a genuine association between cognitive status and impairment level speech phenomena in PD. Extant knowledge regarding these potential effects remains equivocal. Further high quality studies in this under-researched area could clarify these potential associations.

My study provided further evidence that many PwPD have difficulty conveying intended emotion in their speech. Previous studies have shown that listeners often form negative impressions of the personality of PwPD (Pentland et al., 1988, Pentland et al., 1987, Tickle-Degnen and Doyle Lyons, 2004, Jaywant and Pell, 2010). Using a very similar design and materials but a larger sample size, I replicated Miller et al's (2008a) finding that PwPD were less effective than controls in conveying emotion. On the other hand, Martens et al (2011) did not find evidence of reduced emotional conveyance as judged by professional listeners, although inter-rater reliability was limited for this task. Unlike in Miller et al's (2007) study, I found no evidence that listeners found it more difficult to judge the emotion people with Parkinson's disease wanted to convey when both audio and visual cues were available. In the context of linguistic meaning, rather than emotional conveyance, Keintz et al (2007) found that the speech of PwPD was more intelligible in audio-visual presentation, although the difference only reached significance for more impaired speakers. Again, the generalisability of these findings is restricted by a sample size of eight. Potential presentation modality effects in the speech of PwPD remain equivocal.

I did not find any significant associations between acoustic characteristics and emotional conveyance. This result is unlikely to be due to sample size limitations because p values for all measures except pause were >0.3 . The relationship between pause and emotional conveyance was in the negative direction, although it did not reach significance ($p=0.15$). It is possible that larger studies could find a significant effect of pause on emotional conveyance. The absence of an association between F_0SD and emotional conveyance was unexpected, given the traditional conceptual association between pitch patterning and emotion.

While Pentland et al (1988) and Tickle-Degnen et al (2004) demonstrated an important effect of non-verbal factors, my study focused on verbal factors. These studies were extended from the realm of personality impression formation to emotional

conveyance per se by Miller et al (2008a). Miller et al's (2008) finding that listener performance was worst for PwPD in the audio-visual condition supported Pentland et al's (1998) and Tickle-Degnen et al's (2004) views regarding the importance of non-verbal factors and extended them to form a theory relating to asynchronicity of audio and visual cues. In addition, Miller et al (2008a) demonstrated this effect in naïve listeners, whereas previous studies had used expert assessors. It is possible that the lack of replication of the presentation modality effect in my study may be due to the predominantly mild speech impairment in my sample, which meant that there would be less asynchronicity of audio and visual cues. On the other hand, it may be that Miller et al's (2008a) finding was an artefact of using a sample size of five.

My study found a significant positive association between cognitive status and emotional conveyance, meaning that listeners were more accurate in identifying the mood intended by PwPD who had more intact cognitive status. My systematic review (see chapter 3) identified only one study that investigated the effect of cognitive status on emotional speech production in PD (Benke et al., 1998). This study found that only PwPD who had impaired verbal memory were impaired in production of emotional prosody. However, correlational analyses only showed a significant association with one cognitive measure: digit-symbol substitution. While the evidence is not yet conclusive, my study provides further evidence of an association between cognitive status and impaired emotional conveyance in PD.

This is consistent with the idea (see section 3.5) that emotional impairments in PD may involve an emotion-specific component as well as a more general cognitive component, thereby involving both the mesocortical and mesolimbic pathways. Möbes et al (2008) also found evidence for a role of emotion-specific as well as motor speech impairment in impaired emotional speech in PD. This study found that PwPD had reduced fundamental frequency range and intensity range in an emotion production task, but not when imitating a professional speaker. No such differences were found in non-emotional speech. However, the task, which involved the production of the name 'Anna' in a happy, neutral or sad way, could be considered relatively artificial. Additionally, the study focused on emotional speech acoustics and did not consider listener outcomes. My study incorporated an investigation of speech acoustics and listener outcomes, considering cognitive status and presentation modality.

Now I shall discuss aspects of my study relating to communication, at the Activity and Participation ICF levels. My study provided evidence that the transfer of CPIB to the UK was successful in terms of classical validity and reliability parameters, as well as participant acceptability as evidenced by QCA results. Baylor et al (2009) found a

moderate significant association ($r_s = -0.68$) between scores on an early draft of CPIB and the Voice Handicap Index (Jacobson et al., 1997). In comparison, I found an association of $r = 0.74$ between CPIB 10 and CES scores. The slightly higher association with CES as opposed to Voice Handicap Index may result from the former being an ICF activity level measure and the latter an impairment level measure.

A full item-response theory validation of CPIB was outside the scope of my study. However, CPIB has been extensively validated to produce a ten-item short form (Baylor et al., 2013b). Moreover, it has been validated in a PD population in both the USA and New Zealand using item-response theory techniques (Baylor et al., 2013a). The validation presented in this thesis was of a more limited nature, to serve as a confirmation of the cross-cultural transferability of CPIB, prior to its use as the primary outcome measure in my study.

QCA CPIB results demonstrated that most participants had no difficulty understanding CPIB and could see its value. Only one participant said that he could not see the value of the scale. Indeed, a few participants said that completing CPIB had made them think about aspects of their communication that they had seldom, if ever, considered before. Although most participants' overall impression of CPIB was positive, many respondents pointed out some questions that either appeared unclear in their communicative context or that did not relate to their own life experiences. A small number of participants queried the appropriateness of the answering categories, as exemplified by the following quotation:

'Questions where there is no personal experience do not have a 'not applicable' option' (Participant 39, male, age 61, moderate speech impairment).

Some participants said that their responses would vary depending on when they took CPIB and would likely be influenced by many factors besides PD. This last point is acknowledged by the creators of CPIB in the instructions to participants (see Appendix 18). Indeed, these instructions do not ask respondents to attempt to dissociate the effect of PD from other speech or health conditions or environmental features. Many participants in my study emphasised the varied influences on their communication, as exemplified by the following quotations:

'Some of my responses could be due to my personality, my education or my poor hearing rather than my condition' (Participant 43, male, age 78, mild speech impairment)

'There are many factors that could cause a decline on the scale- temporary and permanent' (Participant 85, male, age 73, mild speech impairment).

One participant questioned the appropriateness of the CPIB instructions, saying that ‘questions aren’t Parkinson’s specific enough’ (Participant 85, male, age 73 mild speech impairment). While explaining CPIB prior to its administration, it was my experience that participants most readily understood it in terms of a pre- versus post-PD comparison, while acknowledging that their communication can vary over the course of the day or from day-to-day and sometimes be affected by temporary conditions. Therefore, it is possible that participants in my study interpreted CPIB in a slightly more PD-specific way than the scale creators intended. Overall PD awareness among the participants in my study appeared high. This may have led to a greater dissociation between the effects of PD and other factors.

When contextualising my QCA CPIB results, one must bear in mind that feedback was provided on a set of 46 candidate items, from which the final ten were selected, rather than on the final CPIB short form. This may account for some negative comments regarding the structure and focus of CPIB, which are illustrated by the following quotations:

‘That was horizon to horizon questions on communication...They were a very wide range of questions. Compared to the other tests it seemed to lack focus’ (Participant 85, male, age 73, mild speech impairment)

‘Some questions repeated- same but put in a different way’ (Participant 71, female, age 72, mild speech impairment).

However, there were positive aspects to the use of the 46 item rather than the final version in this context. Feedback on the long form can assist the cross-cultural validation of the short form of CPIB, by demonstrating that problematic items were removed during scale finalisation. It also assessed whether the item set that was considered unproblematic in the original American cultural setting was also unproblematic for participants in a UK setting.

Some questions were considered problematic by some participants in my study. Predominantly issues related to a lack of contextual clarity or personal experience. However, one respondent considered ‘visit with’ in question 35 to be an Americanism, in addition to stating that the question lacked contextual clarity. Questions five, six, eight, ten, 12, 13, 16, 19, 22, 25, 28, 32, 35, 38 and 42 were considered problematic by at least one participant (see Appendix 18 for question list). Of these, questions eight, ten, 16, 38 and 42 were included in CPIB10. This suggests that CPIB finalisation removed most problematic items and that this transferred relatively successfully across cultures.

One participant said that question eight ‘Communicating when you are out and about in your community (e.g. errands; appointments)’ did not relate to her current experience. One participant said that question ten ‘Giving someone DETAILED information’ was contextually unclear, and that his answer would depend on who the other person was. Contextual vagueness was also highlighted in questions 38 ‘Communicating in a small group of people’ and 42 ‘Talking with people you know’. The difficulty with question 16 related to overlap with another question that was not included in CPIB10. None of the final CPIB10 items was considered problematic by more than one participant.

My study adds to the developing international evidence base that CPIB is a valid and useful measure of communicative participation in PD. Additionally, the QCA results add an alternative perspective which enriches extant knowledge. A moderate concordance between CES and CPIB scores, as well as dissociations between cognitive results using CES and CPIB measures (see below), provide evidence for a conceptual distinction between communicative effectiveness (ICF Activity level) and communicative participation (ICF Participation level).

Seventy one per cent of PwPD in my study had mild speech impairment, 22% had moderate speech impairment and 7% had severe speech impairment. CPIB scores indicate that the average impact of PD on communicative participation across CPIB10 items was ‘not at all’ for 24 %, ‘a little’ for 53%, ‘quite a bit’ for 20% and ‘very much’ for two per cent of participants in the full study sample. This indicates that, while the majority of participants in my study had mild speech impairment, three quarters of participants found that PD had at least some impact on their communicative participation. As discussed below, my study also demonstrated only a moderate association between speech impairment and communicative participation.

When interpreting these profiles, one should consider the possibility that some PwPD in my study could have had no speech impairment. The absence of physical speech impairment does not necessarily imply preserved communicative participation. The inclusion criteria for my study (see section 4.4.2) stated that participants should have some degree of speech or communication difficulty. Since it is difficult for non-specialists to differentiate between speech and communication, I did not mandate that both aspects should be affected. The phrasing of this inclusion criterion on the participant information leaflet says that eligible potential participants should answer positively to the questions “Do you find that people have more difficulty understanding what you say than they used to?” or “Do you find that people ask you to repeat what you say more often than they used to?”. This phrasing has an emphasis on speech rather than communication. As with

all inclusion criteria that rely on potential participant self-report, one cannot definitively exclude the possibility that a small number of PwPD without speech or communication difficulties could have participated in the study.

I identified only two previous studies that offered a qualitative perspective on communicative changes associated with PD. In both cases, papers lacked detail on the particular qualitative analysis method employed and its epistemological foundations, although it would appear that either thematic analysis or qualitative content analysis was conducted. Miller et al (2011c) found that 87% of respondents felt that at least some aspect of their communication had changed. Reduced loudness was the most frequently cited physical speech difficulty. PwPD mentioned reduced participation in conversations, increased effort, cognitive and psychological factors, as well as a greater impact on some communicative situations, such as using the telephone or public speaking, than others. Miller et al (2006) characterised the impact of PD on communication under four key themes, relating to interacting with others, conversational difficulties, feelings about intelligibility and voice.

My communication QCA results revealed seven key themes relating to speech and communication in PD. These were physical speech impairment, social psychological factors, communicative context, communicative effectiveness, cognition, effort and PD pathway. These findings broadly corroborate the extant results presented above. However, they offer a more detailed delineation of factors and confirmatory evidence from a different setting and sample. This is important in qualitative research, in which conclusions are tied to their context and the generalisability of findings to new contexts is left to the reader's judgement (see section 4.3.3).

As discussed in chapter three, extant knowledge about the relationships between cognitive status, and communicative activity and participation was limited. These formed the primary research question in my study. With regard to communicative participation, I highlighted particular challenges with regard to cognitive and outcome measure selection. As discussed in section 7.2.1, I believe that I have met these challenges.

My systematic review (see chapter three) identified two studies that investigated the ICF participation level. Miller et al (2008, 2011) found that MMSE score did not predict change in self-rated communication score at follow-up. However, as discussed in section 4.6.4, MMSE is a relatively insensitive measure of cognitive status in PD. The outcome measure asked participants to describe their communication in terms of a series of adjective pairs, such as 'talkative' versus 'quiet'.

While this clearly investigates psychosocial aspects of communication in PD, which few studies have done, it does not address a question fundamental to communicative participation. This is the extent to which PD has interfered with performing a range of everyday communicative tasks, from the perspective of participation rather than activity. Whitworth et al (1999) found that people with Lewy body dementia retained fewer pre-morbid communicative situations than PwPD and 'subcortical dementia', which may be seen as a conceptual precursor of mild cognitive impairment. However, the outcome measure was rather superficial. My study has extended the frontier of knowledge about the relationships between cognitive status and communicative participation, with regard to the cognitive and outcome measures I selected. My study provides evidence for a role of cognitive status in reduced communicative participation in PD. This suggests that the negative result of Miller (2008, 2011) may be a consequence of measure selection.

Studies of the ICF Activity level in my systematic review (see chapter three) focused on pragmatics and conversation management rather than more global communicative effectiveness. Although communicative participation is a greater focus of my thesis than communicative effectiveness, my study is, to my knowledge, the first to assess the relationship between cognitive status and overall communicative effectiveness in PD. As discussed below, my study was inconclusive with regard to this relationship. However, it suggests that executive aspects of cognitive function may be less important for communicative effectiveness than for communicative participation.

My study demonstrated dissociations between results using activity and participation measures. Total MoCA score significantly predicted CPIB score, but not CES score. Visuo-spatial/executive and attention MoCA sub-domains significantly predicted CPIB score, whereas MoCA naming sub-domain score significantly predicted CES score. It appears that communicative participation and communicative effectiveness are distinct concepts, which may recruit different cognitive resources. To my knowledge, these detailed relationships have never been investigated. Neither has the role of social cognition in communicative participation.

It is possible that the apparently contradictory results regarding the relationships of MoCA total and sub-domain scores to communicative outcomes could result from the domain weightings of MoCA. My study suggests that executive aspects of cognition may be important for communicative participation, whereas naming was the only sub-domain that significantly predicted communicative effectiveness. Total MoCA score predicted CPIB but not CES. In MoCA, five points are given for executive and visuospatial function,

three points for naming, six points for attention, three points for language, two points for abstraction, five points for delayed recall and six points for orientation.

Since other domains besides executive and visuospatial function are believed to draw considerably on executive function, it could be claimed that MoCA is weighted towards executive aspects of cognitive function. Therefore, the non-significant association between total MoCA score and CES may result from the apparent stronger associations with non-executive cognitive functions for CES, compared to CPIB. Sub-domain analyses must be interpreted cautiously, in the absence of thorough neuropsychological investigation. MoCA consists of seven sub-domains: visuospatial-executive, naming, attention, language, abstraction, delayed recall and orientation.

The DSM-5 criteria for minor neurocognitive disorder (American Psychiatric Association, 2013) profile cognition using six domains: complex attention, executive function, learning and memory, language, perceptual-motor function and social cognition. The MDS criteria for mild cognitive impairment (Litvan et al., 2012) profile cognition using five domains: attention and working memory, executive function, language, memory and visuospatial function. With the exception of minor grouping differences, MoCA corresponds well to these criteria. The DSM-5 criteria also include social cognition, which does not form a part of MoCA or the MDS criteria. Additionally, MoCA introduces differential weighting of cognitive domains.

Read sentence intelligibility did not predict communicative effectiveness or participation scores. The relationship between conversational sentence intelligibility and communicative outcomes was moderate. The association was greater for effectiveness, predicting 43 % of variance in CES score, than for participation, predicting only 19 % of variance in CPIB score. This provides further evidence of the conceptual distinction between communicative effectiveness and communicative participation. It appears that communicative participation involves a much wider range of physical and psychosocial factors, thereby reducing the association with intelligibility. It is notable that in so far as intelligibility did predict communicative outcomes, it was semi-naturalistic conversational speech intelligibility, rather than reading artificial sentence lists. It is important for speech research to use tasks that approximate real life situations as closely as possible.

Miller et al (2007) found only a weak but statistically significant association between intelligibility and change in perception of self as a communicator after the onset of Parkinson's disease, with no association with change from baseline to the three-year follow-up. This suggests that psychosocial factors may play a greater role than impairment level factors as defined by the ICF. Donovan et al (2005, 2008) found that

sentence intelligibility scores did not significantly predict communicative effectiveness scores (ICF activity level), although a marginally significant result ($p=0.1$) was found for spontaneous speech intelligibility. Therefore, the results of my study corroborate previous results that the relationships between intelligibility and measures of communicative effectiveness and participation are modest. This emphasises that many factors beyond physical speech impairment impact upon communication.

As discussed in section 2.3.1.1, diagnostic criteria for mild cognitive impairment often mention limited impact on everyday life as one differentiating factor from a diagnosis of dementia. My CPIB and QCA experiences results provided evidence that many of the participants in my study had significantly reduced participation in everyday life situations. Although the immediate context was communicative participation, as supported by the QCA results, the role of communication in life is so profound that limited communication can have a pervasive impact on life.

However, these findings are not incompatible with the dominant view of mild cognitive impairment. In a condition as complex of Parkinson's disease, it is problematic to claim that mild cognitive impairment necessarily leads to a significant impact on everyday life. Activity and participation limitations are also associated with impairments of mobility, communication and other non-motor symptoms. The overall effect is likely to be the result of a combination of factors including mild cognitive impairment. However, this does not exclude the possibility that the impact of mild cognitive impairment may be more profound than currently conceptualised in diagnostic criteria.

Rosenthal et al (2010) assessed the functional significance of mild cognitive impairment in Parkinson's disease. This large-scale study found that cognitive status as measured by the Dementia Rating Scale-2 (Jurica et al., 2001) was moderately associated with impairment of activities of daily living in people with Parkinson's disease without dementia. The effect was greater for instrumental rather than basic activities of daily living. Whereas basic activities of daily living relate to fundamental self-care functions, instrumental activities of daily living are more complex functions that are not essential for functioning, but facilitate independent life in the community (Bookman et al., 2007). Leroi et al (2012) compared quality of life, extent of disability and caregiver burden in people with Parkinson's disease with dementia, mild cognitive impairment and intact cognitive status. This large-scale study found that while quality of life and caregiver burden only differed between those with and without dementia, global extent of disability differed significantly between all groups. It is possible the conceptualisation of mild cognitive impairment could move away from the notion that it must not significantly impact functional independence. Unlike the DSM-5 (American Psychiatric Association, 2013),

Petersen et al (1999) and Alpert et al (2011) criteria, the MDS (Litvan et al., 2012) criteria for mild cognitive impairment do not include this tenet.

I shall now discuss the importance of communication in everyday life. The first indicators of standard of living such as the Level of Living Index (Drewnowski and Scott, 1966) were based on physical needs. This is based on the premise that only once basic physical needs are satisfied, can higher ethical, artistic and spiritual needs be addressed (Maslow, 1943). Durkheim's homo duplex dichotomy (Durkheim, 1995) argues that the person is always split between egoist principles and moral conscience. Even satisfaction of basic needs is culturally determined and varies markedly between countries (Douglas and Ney, 1998a). People's desires and needs are determined and their prioritisation shaped by other people and society (Douglas, 1986). This involves a process of negotiating shared values, priorities and standards (Douglas and Ney, 1998a). The individual "carries a legacy of institutions from past generations of other persons" (Douglas and Ney, 1998b). Dasgupta (1993) shifts the focus of human wellbeing from individual to social factors. "A social being has one prime need- to communicate" (Douglas and Ney, 1998c). Therefore, communicative deficits threaten to undermine a key human function. It is unsurprising that Miller et al (2006) found that people with Parkinson's disease were not predominantly concerned about impairment level changes in their speech, but rather how these affected their self-concept and participation in everyday communicative situations.

The impact of PD on communication is relevant to all healthcare providers who treat PwPD. There is international evidence from several studies that speech and communication impairments in PD affect the patient-practitioner relationship. Pentland et al (1987) found that Scottish health professionals watching silent videos judged PwPD to be less intelligent and to have a more negative personality than cardiac patients, even though these judgements did not associate with the results of standardised psychological tests. Tickle-Degnen and Doyle Lyons (2004) found that American healthcare professionals' judgements of personality were overly affected by reduced facial expression in PD, this effect being stronger in novice practitioners. Mott et al (2004b) found that Australian PwPD reported loss of facial expressiveness to be more troublesome than difficulty being understood or swallowing. Participants reported they felt that non-specialist healthcare professionals often didn't fully understand what it was like to have the condition. The examples above demonstrate how fundamental communication is to humanity and how pervasive the impact of communicative impairment can be.

As discussed above, communication is fundamental to humanity. Moreover, a particular aspect of communication that I have called communicative participation is crucial to my thesis. In closing this section, I shall discuss what participation actually means. In contrast to the traditional medical model, social models (Oliver, 1996) differentiate between impairment and disabled experience, the latter involving disruption of personal identity (Scully et al., 2004, Bury, 1982). The distinction between impairment, activity and participation has been incorporated into ICF. In ICF (p123), impairment relates to body structures and functions, “activity limitations are difficulties an individual may have in executing activities” and “participation restrictions are problems an individual may experience in involvement in life situations”. Hammel et al (2008) interviewed people with a range of disabilities and derived a model of participation as a cluster of values relating to freedom, integration, engagement, responsibility and influence. This suggests that participation is a multifaceted concept that may mean different things to different people, rather than being a monolithic idea that is simple to define and measure.

7.4 Future directions

Communicative participation was the key outcome measure in my study. I found that read sentence intelligibility did not predict communicative effectiveness and participation, and that conversational intelligibility was only a modest predictor of communicative outcomes. This adds to the extant body of literature (see section 2.4.2.7) emphasising the importance of communicative participation, rather than focusing on the ICF Impairment level.

For the sake of concision, discussion of clinical practice in this section is exclusively from a UK perspective. Current clinical guidelines for speech and language therapy in the UK (Royal College of Speech and Language Therapists, 2005, Royal College of Speech and Language Therapists, 2006) do not contain a specific section on PD. There is the potential of over-generalising across conditions that do not share the same pathogenesis. While PD is an acquired motor speech disorder and a progressive neurological disorder, as seen in chapter 2, it is a wide-ranging condition which may impact on autonomic function, cognitive status and psychiatric status. Therefore, more specific guidance for PD may be beneficial, especially in the light of extensive investigations of communication in PD since the publication of these guidelines, most notably by Professor Nicholas Miller and colleagues at the University of Newcastle.

While no specific guidance is given for the treatment of individuals who have cognitive impairment as part of a progressive neurological condition, guidelines for speech and language therapy with clients with dementia recommend specific focus on

conversation to enhance communication. Guidelines for clients with dysarthria recommend perceptual evaluation of speech impairment, a communication skills profile and a focus on the psychosocial impact of the condition. Recommended treatment may be physiological, compensatory strategies or involve the use of augmentative technology. Service organisation guidance for clients with progressive neurological conditions recommends promoting and maintaining functional independence as far as the condition allows. Service organisation guidance for clients with acquired motor speech disorders emphasise that impairment should be sub-ordinate to activity and participation.

However, recent systematic reviews conclude that there is still insufficient high-quality evidence to conclusively support the efficacy of speech and language therapy in PD or to determine which therapy techniques are the most effective (Herd et al., 2012a, Herd et al., 2012b). Moreover, the mechanisms of action remain unconfirmed. A recent national survey of the practices of 185 UK speech and language therapists with regards to PD (Miller et al., 2011b) found that assessment tools beyond the ICF impairment level were used by relatively few therapists and that psychosocial issues did not frequently form a prominent focus of therapy relative to impairment-level aspects of speech. However, the vast majority offered some psychosocial support either through group therapy, counselling, discussion, work with the family or referral to other services. Miller et al (2011b) suggest that many therapists may not emphasise communicative activity and participation sufficiently, relative to guidelines. There is anecdotal evidence from people working in the field that the introduction of the ICF has led to an increased focus on activity and participation in the education of student speech and language therapists, with consequent beneficial effects on the service offered by newer recruits to the profession. However, concrete intervention approaches at the participation level appear to be lacking.

As reported in this thesis and in Baylor et al (2013a), CPIB shows promise as a valid and reliable assessment tool for communicative participation in PD. My QCA also demonstrated satisfactory participant acceptability for CPIB. Although this thesis and the extant body of literature support a focus on communicative participation, it is unclear whether this should involve the use of a standardised assessment tool. In a grounded theory investigation of what participation meant to people with a range of disabilities (Hammel et al, 2008), respondents stated the importance of being able to define participation themselves rather than having to meet prescribed societal expectations of what participation should mean. This raises questions about whether a set-item questionnaire such as CPIB is the best way to address the assessment of communicative participation with clients, or whether an open discussion would be more suitable. Potentially, future research could address the relative merits of these two approaches.

As a cross-sectional investigation, my study does not offer definitive evidence of causal relations between cognitive status, speech impairment and communicative outcomes. Therefore, it may be worth considering embedding speech impairment and communicative participation into a natural history study of PD using an incident cohort. This would provide a clear pathway of the temporal sequence and prevalence of speech and communicative impairments, and clarify the causal relation with cognitive status. Additionally the use of a thorough neuropsychological assessment, meeting the level two MDS criteria (Litvan et al, 2012), could help clarify which aspects of cognitive function are most important for speech and communicative outcomes. As discussed in section 7.3, an assessment of social cognition could also be included.

It would be worth conducting a further investigation of the relationships between the acoustic characteristics of the speech of PwPD, since this aspect of my study was limited by resource constraints. The use of a team of phonetic analysts would enable a larger sample size to be analysed phonetically. More resources would enable an age-matched group of assessors to be recruited from a different region of the country. This could be incorporated as an assessment of the mechanism of action of speech and language therapy as a component of a randomized controlled trial of speech and language therapy techniques for PD. There have been on-going bids for a randomised controlled trial, and the potential of incorporating a mechanism of action component has been discussed.

Once associations between cognitive status and a range of other PD outcomes have been clarified, including the pathway to dementia (see section 2.3.1.4), further research could be conducted into identification and treatment of cognitive impairment in PD. An audit of current cognitive screening procedures could be performed, and subsequent research conducted to identify the optimal time and tools to identify mild cognitive impairment in PD. An MDS evidence-based review (Seppi et al., 2011) concludes that rivastigmine is the only pharmacological treatment for dementia in PD for which there is sufficient extant evidence of efficacy to recommend clinical use. Further research could be conducted into potential treatments for earlier cognitive impairment in PD, including pharmacotherapy, cognitive training and exercise.

Additionally, I obtained consent from all participants for audio-visual recordings made as part of my study to be used for responsible teaching and further research purposes. Excerpts from my recordings could be used by my supervisors or other staff, to increase the familiarity of allied health and nursing students with the speech of PwPD. This could bring significant educational benefit and improve the future clinical practice of these students.

7.5 Criteria for a doctorate

The European University Association's (2004a) 'Dublin' descriptors provide a set of international criteria for a research doctorate. I shall address each of these in turn, demonstrating how my work fulfils these criteria.

The first criterion is to "have demonstrated a systematic understanding of a field of study and mastery of the skills and methods of research associated with that field" (European University Association, 2004b). In this thesis, I performed a systematic review (see chapter 3) of extant knowledge in the field prior to my study. Dr Deane stated that this was a particularly challenging systematic review and that I required advanced research skills to complete it successfully. Additionally, my study includes a wide range of research methods which I had to master. I conducted detailed systematic phonetic analysis and oversaw listener assessment (see chapter 5). I also performed a range of statistical analyses (see chapter 6).

The second criterion is to "have demonstrated the ability to conceive, design, implement and adapt a substantial process of research with scholarly integrity" (European University Association, 2004b). I developed the project presented in this thesis from a brief advertised project proposal to a complete study design. I also oversaw some changes in focus during the project planning phase. I rationalised the proposed listener assessment design to focus on key research questions and address practical challenges, thereby eliminating the proposed expert listener group. I introduced an investigation of emotional conveyance into the design to complement intelligibility. Moreover, I expanded the role of communicative effectiveness (ICF Activity level) to complement communicative participation (ICF Participation level). As Chief Investigator and project manager, I oversaw the implementation of this multi-faceted project.

The third criterion is to "have made a contribution through original research that extends the frontier of knowledge by developing a substantial body of work, some of which merits national or international refereed publication" (European University Association, 2004b). My study builds relationships between previously largely unassociated concepts and challenges traditional assumptions about the nature of speech and communicative impairment in Parkinson's disease. I have presented my systematic review and study results as posters at national and international conferences. This June I presented two posters at the 17th International Congress of Parkinson's Disease and Movement Disorders in Sydney, Australia. After submission of this thesis, I will commence preparation of manuscripts for submission to peer-reviewed journals. I

intend to publish my systematic review, main results paper and some papers on more specific aspects of my study.

The fourth criterion is to be “capable of critical analysis, evaluation and synthesis of new and complex ideas; can communicate with their peers, the larger scholarly community and with society in general about their areas of expertise” (European University Association, 2004b). My systematic review and discussion chapters provide evidence of successful critical analysis, evaluation and synthesis. In addition to the conferences mentioned above, I have given presentations locally for a variety of academic, clinical and public audiences.

The fifth and final criterion is “to be able to promote, within academic and professional contexts, technological, social or cultural advancement in a knowledge based society” (European University Association, 2004b). As discussed in section 7.3, the results of my study have the potential of contributing to future clinical advances. Moreover, the knowledge gained through my study constitutes a significant advance in extant scientific knowledge about a topic which has clear social and cultural relevance. As mentioned above, I have started the process of disseminating my findings in both academic and non-academic contexts.

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7.6 Concluding remarks

In this study, I investigated relationships between cognitive status, speech and communication in PD. The primary research question was ‘How does cognitive status associate with the communicative effectiveness and communicative participation of PwPD?’. I found evidence that decline in cognitive status, especially executive functions, appeared to associate with reduced communicative participation. The association between cognitive status and communicative effectiveness was less clear. I also assessed acoustic speech characteristics, intelligibility and emotional conveyance, both with regard to differences between PwPD and CPs and the role of cognitive status in PD. The role of cognitive status in ICF Impairment level speech performance was largely restricted to emotional stimuli and unnatural reading tasks.

There was only a modest association between intelligibility and communicative measures. This was only found for conversational not read sentences. My study provides

evidence of clear associations between ICF Impairment, Activity and Participation level concepts along the pathway from motor and cognitive impairment through speech impairment to reduced communicative effectiveness and participation. These results along with other extant findings could be applied to help advance speech and language therapy for PwPD. These improvements could include a greater focus on communicative participation and a clearer understanding of mechanisms of action and which aspects of speech to target.

Appendices

Appendix 1: Medline search strategy for systematic review

(exp parkinson's disease/)

AND

(exp cognition/ OR exp dementia/ OR exp attention/ OR exp memory/ OR exp memory disorders/ OR exp motor skills/ OR cognitive decline.mp. OR cognitive deficit.mp. OR exp personality disorders/ OR exp neuropsychology/ OR exp problem solving/)

AND

(exp communication/ OR exp communication disorders/ OR exp language/ OR speech perception/ OR speech acoustics.mp OR exp Speech Characteristics/ OR speech intelligibility.mp. OR communication impairment*.mp. OR communicative impairment*.mp. OR communicative function*.mp. OR exp semantics/ OR communication participation.mp. OR communicative participation.mp. OR exp linguistics/)

Appendix 2: Systematic review characteristics table

Study	Location	PD criteria	Cognition criteria	General Inclusion Criteria	Demographics (PD, CON) For N, male in brackets	Method	Aim	Comments
Alpert 1990	USA	IPD (H&Y 3-4)	Mild to moderate dementia	No psychiatric conditions or substance abuse	N 10(8) Age 77 DUR 6	Cross-sectional	To assess the impact of dementia on communication in PD	
Benke 1998	Austria	Clinically assessed IPD. Responsive to medication.	Non-demented (Clinical Dementia Rating)	No other psychiatric or neurological or substance problems. Normal hearing and normal or corrected sight	N 48 (9),18 (8) Age 62,61 EDU 10,9 DUR 10,NA	Mixed factorial	To assess the impact of cognitive impairment on emotional recognition by PwPD	PD subdivided into 2 groups by verbal learning. CON had chronic non-CNS conditions
Breitenstein 2001	USA	Clinical diagnosis of IPD Onset after 55	MMSE 27	Right-handed, normal hearing. Not fluent in	N 20(13), 16(8) Age 71,69 DUR 1, NA	Mixed factorial	To investigate the impact of temporal processing and executive function on	

				German			emotion recognition in PD	
Dara 2008, Monetta 2008	Canada (English language)	Mild to moderate IPD (Calne et al 1992)	Not demented (DRS)	Native English speakers. No other serious medical or substance conditions. Normal or corrected vision and adequate hearing	N 16 (9), 17(10) Age 66, 67 EDU 15, 16 DUR 8, NA H&Y 3, NA	Mixed factorial	To assess the impact of PD on emotional speech processing and pragmatic functioning	
Hall 2011	USA	IPD (Geld et al 1999)			N 17 (12), 17(4) Age 61, 59 DUR 8, NA H&Y 3, NA	Cross-sectional	To investigate pragmatic communication in PD	
Kan 2002	Japan	PD (H&Y 2-3)	MMSE 23	No significant visuospatial deficit	N 16(5), 22(10) Age 69, 64	Mixed factorial	To investigate emotional recognition in PD	

Lesser 1999; Whitworth 1999	UK	IPD			N 12 (9) Age 72	Qualitative	To investigate the impact of cognitive impairment on conversation abilities in PD	PD subdivided into 2 groups by cognitive status
McKinlay 2009	New Zealand	Neurological diagnosis of IPD (H&Y 1-4).	Not demented (MMSE 25, DRS, DSM-IV)	Native English speakers aged 50-80. No significant medical or psychiatric conditions or learning disability. Adequate or corrected hearing and vision	N 40, 40 Age 66, 67 EDU 14,14 Paired matching for age, estimated premorbid IQ and current mental status	Cross-sectional (matched pairs)	To investigate the impact of cognitive impairment on pragmatics in PD	
McNamara 2003	USA	Clinically diagnosed IPD	Non-demented (DSM-III)	Male and right-handed. No substance	N=20,11,10 Age 72,63,48 EDU 13,14,13	Cross-sectional	To investigate the impact of frontal cognitive	Two separate samples of PwPD were

				abuse or head injury. Second PD sample not depressed	DUR 9,NA,NA		impairment on pragmatic communication in PD.	used.
Miller 2007,2008, 2011	UK	UK brain bank criteria for PD		Native English speakers. No other neurological, cognitive or speech-language problems	N=125,40,58 Age 72,70.58 DUR 8, NA,NA H&Y 3, NA,NA	Cohort	To assess the impact of factors including cognition on intelligibility and communication in PD	Two control samples were used. PD sample size varied.
Pell 2003	Canada (English Language)	Neurological diagnosis of mild IPD- Calne et al (1992)	Non-demented (DRS)	No other serious medical or substance problems. Adequate hearing	N 21(11), 21 (11) Age 62, 62 EDU 16, 16 DUR 4, NA H&Y 2, NA	Mixed factorial (matched pairs)	Investigating the role of the basal ganglia circuits in processing of emotional prosody	
Yip 2003	Hong Kong (Cantonese)	Clinical diagnosis of IPD		No other neurological or psychiatric	56 (33), 56 (33) Age 64, 65	Mixed factorial	To investigate emotional recognition in	

				conditions. Right- handed.	EDU 8, 8 DUR 7, NA Median H&Y 3		PD	
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Appendix 3: Systematic review results table

Study	Cognitive, speech and communication measures	Results
Alpert 1990	Composite dementia scale (modified MMSE and UPDRS Intellectual Impairment), VOXCOM and WELMAR parameters	Cognitive impairment was negatively associated with frequency of internal pauses and frequency of simultaneous speech, and positively associated with mean length of internal pauses.
Benke 1998	Equivalent of California Verbal Learning Test, Wechsler Digit- Symbol Substitution, Raven's Progressive Matrices and Hooper Visual Organization Test. Recognition and production of emotional prosody	Only PwPD with impaired verbal memory were impaired in production and recognition of emotional prosody. However the only significant association was between Digit-Symbol Substitution and prosodic production
Breitenstein 2001	Composite executive function score, MMSE, WAIS picture completion and digit span. Identification of emotional prosody	Only moderate PwPD were significantly impaired in the identification of emotional prosody. Executive function score predicted 45% of the variance, being more predictive in the incongruent context condition. More general cognitive measures were not significantly associated with performance
Dara 2008, Monetta 2008	DRS, listening span, Color Trail-Making Test, Tower of London, Warrington Recognition Memory Test, Benton Phoneme Discrimination and Face Recognition, forward digit span and verbal fluency, Emotion identification and Discourse	PwPD were impaired in emotional prosody recognition only in the absence of congruent verbal cues. PwPD rated anger, disgust and fear stimuli more positively than controls. No significant association between executive function and linguistic emotional recognition was found. There was a marginally significant result for working

	Comprehension Test	memory and pure prosody identification to associate. Only PwPD with impaired working memory were impaired on the Discourse Comprehension Test. There were no significant whole group effects or differences between PwPD with unimpaired working memory and controls. A moderate significant correlation was found between verbal working memory and performance on inference and detailed questions
Hall 2011	MMSE and Rating Scale of Pragmatic Communication Skills.	PwPD were significantly impaired on the Rating Scale of Pragmatic Communication Skills, correlating strongly with MMSE scores
Kan 2002	MMSE and Prosodic emotion recognition	PwPD did not differ significantly from controls in prosodic emotion recognition. MMSE scores did not significantly associate with outcomes
Lesser 1999; Whitworth 1999	Semantic, grammatical and intelligibility tests, carer-rated communication questionnaire and CAPPCL coding of conversation parameters	Overall the PD 'subcortical dementia and Lewy Body Dementia (DLB) groups did not differ on Conversation Analysis or single word semantics parameters. However the DLB group had more difficulties in orienting the conversation partner to a new topic, in sentence processing and retained fewer pre-morbid communicative situations
McKinlay 2009	ID/ED, reading span, processing speed, word and colour naming. TLC.	PwPD were impaired on TLC overall and on the making inferences, oral expression and figurative language subtests but not on ambiguous sentences. Processing speed, reading span and attention set-shifting significantly associated

		with TLC total as well as the ambiguous sentences, making inferences, and figurative language sub-test scores. Processing speed and attention set-shifting also significantly correlated with the oral expression sub-test score. However no overall between-group difference in set-shifting was found
McNamara 2003	Verbal fluency, design fluency, MMSE, Stroop, Tower of London and Prutting and Kirchner's (1987) Pragmatic Protocol	PwPD were found to be significantly impaired in the pragmatic protocol. Significant corrected correlations were found with Stroop test and Tower of London time to first move and time per move. PwPD were shown to overrate their pragmatic abilities relative to their spouses' ratings.
Miller 2011; 2008; 2007	MMSE, self-rated questionnaire about self-image as a communicator, listener- and self-rated intelligibility and disordered speech ratings	There was a significant reduction in self-perception as a communicator score after the onset of PD but no significant further change at the three-year follow up. MMSE did not significantly predict communication change score. PwPD were found to have reduced listener- and self-rated intelligibility and increased disordered speech ratings. MMSE was found to be a significant predictor of listener-rated intelligibility
Pell 2003	DRS, digit span, verbal working memory span, Trail Making Test and Wisconsin Card Sorting Test. Emotion identification, emotion discrimination from well-formed and nonsense sentences and emotional stimulus	In nonsense sentences PwPD were significantly impaired in emotional identification with a marginally significant result for discrimination. In well-formed sentences there was a marginally significant result for impaired identification. PwPD were significantly affected in emotional feature rating of

	feature rating	disgust and sadness. A significant moderate correlation with auditory working memory was found except for the feature rating measures
Yip 2003	Hooper Visual Organization Test, Judgement of Line Orientation, Balloons Test and digit span. Emotional discrimination and identification	PwPD were impaired on prosodic emotional identification and discrimination, especially sadness perception. Forward and backward digit span did not significantly predict prosodic emotional recognition. The contribution of other cognitive measures specifically to prosodic as opposed to facial emotional recognition is not presented

Appendix 4: Invitation letter for conversation partners



Factors affecting the speech of people with Parkinson's disease

Dear

We would like to invite you to take part in some research about things that affect the speech of people with Parkinson's disease. The study would involve a single meeting which would take place either in your home or at the University of East Anglia depending on your preference.

We need comparison speech samples from people who do not have Parkinson's disease. You have been identified by a person with Parkinson's disease as somebody they are happy to have a conversation with.

The study would involve:-

- Reading some sentences and having a conversation with the person with Parkinson's disease who has invited you to take part. This speech would be filmed by the research team member.
- Completing one background information questionnaire and, if asked, assisting the person with Parkinson's disease in the completion of some questionnaires.

We estimate that on average the speech recordings would take around 15 minutes and the questionnaires would take around 30 minutes. However, we recognize that people take different amounts of time. Before the study procedures start, you would have the opportunity to discuss the study with a member of the research team to ensure that you understand what you would be expected to do and are happy to take part.

For further information, please read the Information Sheet. If you think that you might like to take part, please return the reply slip to the research team in the pre-paid envelope provided.

Yours Sincerely



Maxwell Barnish

Principal Investigator

Queen's Building

Faculty of Medicine and Health Sciences

University of East Anglia

Norwich NR4 7TJ

..... ✂

Reply Slip

I would like a member of the research team to telephone me to answer any questions I have and if I am still interested, to make an appointment to take part in the study.

Name:-


Telephone number:-


Day and time preference for the call:-


Please put this slip into the prepaid envelope and a member of the research team will telephone you shortly after receipt of the reply slip

Appendix 5: Participant information leaflet for people with Parkinson's disease

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 Our Vision
 To provide every patient
 with the care we want
 for those we love the most

Norfolk and Norwich University Hospitals 
 NHS Foundation Trust


 University of East Anglia

Factors affecting the speech of people with Parkinson's disease

We would like to invite you to take part in a research study. Before you decide whether to participate you need to understand why the research is being done and what it will involve for you. Please take time to read the following information carefully. Talk to others about the study if you wish.

Part 1 tells you the purpose of this study and what you will be asked to do if you take part

Part 2 gives you more detailed information about the conduct of the study. Please do ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Thank you for reading this.

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Part 1:

1.1 What is the research for?

Many people with Parkinson's disease say that their speech and ability to talk with people are badly affected by the condition. Studies have shown a number of factors that influence speech and language, but few have tried to get an overall view of the influencing factors and link them with people's ability to talk in real life settings. We know that issues such as how severe your Parkinson's is, how your mood is, and how well you are able to remember things, pay attention, and problem solve (cognition), can all affect speech. We want to measure these things and make a video recording of you speaking so we can see what factors are most influential in causing the speech problems. We also want to investigate what makes speech more or less understandable for others. We hope this will allow speech and language therapists to develop a better understanding of what causes speech problems for people with Parkinson's disease, and so target their therapy more effectively.

Secondly, there is currently no easy way for speech therapists to measure how much speech problems affect how you talk in the real world, e.g. can you talk on the telephone to your grandchild, or in a crowded room to a stranger? So as one small part of this study we will check that a recently developed assessment measure from the USA will work in a British setting and with people with Parkinson's disease.

1.2 Why was I chosen?

You have been invited to participate because you have Parkinson's disease and are a patient at the Norfolk and Norwich University Hospital.

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1.3 Do I have to take part?

No, it is up to you to decide. You have the right to choose whether or not you would like to participate in this study. We will describe the study in this information sheet, and we will then go through it with you before we start any of the research. If after this you decide you would like to take part, we will then ask you to sign a consent form to show you have agreed. You are free to withdraw at any time, without giving a reason. This will not affect the standard of care you receive.

1.4 Who can take part?

We need to recruit people with Parkinson's disease who have some difficulty with their speech and language. Please answer the two following questions:

1. Do you find that other people have more difficulty understanding what you say than they used to?
2. Do you find that people ask you to repeat what you say more often than they used to?

If you answered "yes" to either question you are suitable for this research study. If you think you might like to take part, please return the reply slip in the pre-paid envelope provided.

We also need conversation partners to join in this study. We would appreciate if you could give the enclosed conversation partner information pack to an adult who you would be willing to have take part with you, such as a partner, son, daughter or friend. This is to provide a comparison speech sample and provide assistance if required with the completion of the questionnaires. However, you are also welcome to take part by yourself if you prefer.

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1.5 What will I be expected to do if I take part?

Step 1:

A member of the research team will then telephone you to discuss the study, answer any questions you may have, and if you are still interested in taking part they will make an appointment to conduct the research. You can have assistance with this telephone call if this would be helpful for you.

Step 2:

The research appointment will be made at a time and day convenient to you and your conversation partner. At the start of this appointment, the researcher will discuss the study with you to ensure you understand it and are happy to take part before we ask for consent. After you give consent, we expect the research procedures to take around 45 minutes. However, we recognize that people take different amounts of time. We are happy to visit you at your home or you can visit us at the Clinical Research and Trials Unit at the University of East Anglia. Any travel costs will be reimbursed.

Step 3: Video Recording

At the research appointment, once you have had sufficient time to discuss the study with us and give consent, you will be filmed reading aloud 16 sentences that will be provided. Then we will ask you to say four sentences in three different ways: a 'happy' way, a 'sad' way and a 'neutral' way.

Then we will ask you to have a brief conversation with the person you have invited to take part or one of the research team about a topic such as "a favourite day out".

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Step 4: Conversation partner recording

If the person you have invited has agreed to take part in the research, we will ask them to also read the sentences aloud, just as you have. This acts as a comparison.

Step 5: Questionnaires.

Then you will be asked to complete some questionnaires. These will help us understand factors that can affect your speech and language, and how you find talking in day-to-day activities. It is important that you fill in the questionnaires as fully as possible. You can have help to complete these if necessary. Your name will not be used on any questionnaires. The research team will have no access to medical records at any stage in the research. The questionnaires will cover the following topics:-

- Background information such as your age, how long you have lived in Norfolk, how many years you have had Parkinson's disease, whether you have any swallowing difficulties, what medication you are currently taking for Parkinson's
- Cognition (How well you can remember things, pay attention and problem solve)
- Mood (How you feel in yourself)
- How Parkinson's disease affects your everyday communication

... the questionnaires will take a total of around 30 minutes to complete.

One of the questionnaires we will ask you to complete will assess your mood. If on completion we find that the result suggests that you may be suffering from

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depression, the researcher will tell you immediately and give you an information sheet which will recommend what you should do next to help with this condition. We will also send a letter to your GP with your agreement.

Step 6:

A fortnight after your research appointment we will send you another copy of one of the questionnaires. It will take about 10 minutes to complete. This is an important part of the process of assessing how good a new scale is. It allows us to see if the scale is reliable and "stable" over a brief period of time. We will provide a prepaid addressed envelope for you to return this to us.

Assessors

Two items in our study are to determine how understandable your speech is to strangers, and whether they can determine your mood (happy, sad, neutral) from the tone of your voice. To do this the video recordings of your speech will be viewed by students and staff who will assess it for intelligibility and mood. The assessors will be recruited from the University of East Anglia and will sign confidentiality agreements and be supervised by a member of the research team. It is unlikely but possible that an assessor could recognize you. Assessors are instructed that it is essential that if this occurs, they must not divulge this information to anyone.

Speech Database

Although we have a plan of investigations we wish to complete on the video recording of you speaking, we recognise that we will not be able to do all possible investigations. We will have to select the most relevant ones for our particular study. We would like to create a secure database that will store the

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video recordings so that in the future other researchers can examine them. Additionally they would be a valuable resource for speech therapy students to learn how to better understand people with Parkinson's disease who have difficulties with their speech.

Facial expressions are a key part of communication. However, obviously, you can be recognised from a picture or video of your face. So although your name would not be stored on the database, the video could allow you to be identified, so we have to treat these data with particular care. Only people that have a legitimate reason to access the database would have access to it, e.g. lecturers, students, speech therapists, researchers.

We are asking you separately for permission to store your recordings on the secure database. If you choose not to donate your recordings to the database, you are still eligible to take part in the main study.

1.5 Are there any risks to me?

We do not predict any risks by joining in this study.

1.6 Could taking part in the study do me some good?

The information we get from this study might help us better understand speech problems associated with Parkinson's disease. This may lead to better assessment and treatment of these speech problems in the future. We cannot

promise that the findings of this study will be of direct benefit to you, but we hope that they will help people with Parkinson's disease in the future.

1.7 Expenses and payments

We will reimburse travel costs if the study visit does not take place in your home

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1.8 What if there is a problem?

Any complaint about the way you have been dealt with during the study will be addressed. The detailed information on this is given in Part 2.

1.9 Will my taking part in the study be kept confidential?

Yes. We will follow ethical and legal practice and all information about you will be handled in confidence. The details are included in Part 2.

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Part 2:

2.1 What will happen if I start being involved in the study but then don't want to carry on with the study?

You can stop taking part at any time and you do not have to give a reason. We will keep the data collected up to your withdrawal. This will not affect the care you receive.

2.2 What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions.

Mr Maxwell S. Barnish

Principal Investigator

Tel: 01603593300 (Monday to Friday office hours)

E-mail: m.barnish@uea.ac.uk

Dr Katherine Deane

Academic Supervisor

Tel: 01603 597047(Monday to Friday office hours)

E-mail: k.deane@uea.ac.uk

In the event that something does go wrong and you are harmed during the research and this is due to someone's negligence then you may have grounds for a legal action for compensation against the University of East Anglia but you may have to pay your legal costs.

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2.3 Will my taking part in this study be kept confidential?

Yes. All information which is collected about you during the course of the research will be kept strictly confidential. All the information we obtain relating to you will be treated in the strictest confidence and stored in line with the Data Protection Act (1998). Only investigators from our team (who have formal legal duties of confidentiality) will have access to this information.

Your name will not be used and you will be identified only by an anonymous code. Questionnaires will be "linked anonymised". This means that we will use a numerical code rather than your name to identify your questionnaires. The link between names and codes will be stored in a locked filing cabinet in a locked room at the university and will only be accessed by members of the research team. When we write articles and give presentations about the project, and when we label your recordings, we will use this code, never your real name.

Data from this research will be stored securely for up to five years after the study is completed to allow us to fully analyse all of the data. After this time the data will be disposed of securely.

There are two circumstances where confidentiality may be broken – but only with your specific permission.

In the first instance, we may wish to present the video of your speech at presentations to research conferences, or as part of our research reports. As your face will be visible, you could be identified, so we will ask for specific permission to do this. If you do not want your video to be shared in this way it

would be kept private and just used in the research and this would not prevent you joining in the rest of the research.

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In the second instance we want to ask you to allow us to preserve the video/audio recordings for the use of future research. If you agree, we will store the recordings in a secure controlled-access database such as the University College London (UCL) Human Communication Audio Visual Archive (CAVA) at UCL Library. We also ask you to give us permission to use these recordings for further analysis in future research projects and for teaching purposes. People who want to use your recordings will sign a licence agreement which means that they will have to respect your confidentiality, rights and dignity, and to use the data in a responsible way. They will only be able to use the data for genuine research and teaching. If you choose to withdraw from the project before the end of the study, the recordings that have already been made will be kept in the archive. Your real name and address will not be kept in the archive.

2.4 What will happen to the results of the research study?

The results of the study will be used as part of Maxwell Barnish's PhD thesis which will be submitted to the University of East Anglia. We will send you a summary of the results of the study, publish the results in research journals to do with speech and health and send a summary of the findings to Parkinson's UK. The results will also be presented at relevant conferences and shared with local professionals. In all of these publications you will not be identifiable unless you explicitly give consent for video recordings to be shown.

2.5 Who is organizing and funding the research?

2.5 Who is organizing and funding the research?

This study is part of a three year PhD studentship project funded by the University of East Anglia. The Chief Investigator is PhD student, Mr Maxwell

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Barnish. Maxwell will work under the supervision of Dr Katherine Deane, Dr Simon Horton and Dr Zoe Butterfint.

2.6 Who has approved the study?

The study has been approved for funding by the Health and Social Sciences Research Institute, University of East Anglia. All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee to protect your safety, rights, wellbeing and dignity. The study has been reviewed and given a favourable opinion by NRES Committee East of England- Norfolk.

2.7 Contacts for Further Information

If you would like to discuss the study or are interested in taking part, please return the reply slip in the pre-paid envelope provided and a researcher will contact you.

If you would like information about taking part in research generally, please contact your GP or the Patient Advice and Liaison Service.

Monday to Friday, Office hours, Tel: 01603 289036, Email Address: PALS@nnuh.nhs.uk

If you decide to take part, thank you for participating in this research project. We would like to thank you for your contribution to research which aims to increase knowledge about factors affecting speech in Parkinson's disease and lead to developments in Speech and Language Therapy.

increase knowledge about factors affecting speech in Parkinson's disease and lead to developments in Speech and Language Therapy for Parkinson's disease. We are also very thankful to those who choose to donate their speech recordings to the database for use in future research.

Maxwell S. Barnish

Principal Investigator


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Queen's Building

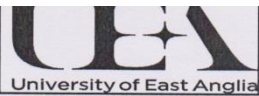
Faculty of Medicine and Health Sciences

University of East Anglia

Norwich NR4 7TJ

 **Thank you for taking your time to read this.**

Appendix 6: Information leaflet for conversation partners



Factors affecting the speech of people with Parkinson's disease

We would like to invite you to take part in a research study. Before you decide whether to participate you need to understand why the research is being done and what it will involve for you. Please take time to read the following information carefully. Talk to others about the study if you wish.

Part 1 tells you the purpose of this study and what you will be asked to do if you take part

Part 2 gives you more detailed information about the conduct of the study. Please do ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Thank you for reading this.

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Part 1:

1.1 What is the research for?

Many people with Parkinson's disease say that their speech and ability to talk with people are badly affected by the condition. Studies have shown a number of factors that influence speech and language, but few have tried to get an overall view of the influencing factors and link them with people's ability to talk in real life settings. We know that issues such as how severe their Parkinson's is, how their mood is, and how well they are able to remember things, pay attention, and problem solve (cognition), can all affect speech. We want to measure these things and make a video recording of both people with Parkinson's disease and healthy volunteers speaking so we can see what factors are most influential in causing the speech problems. We also want to investigate what makes speech more or less understandable for others. We hope this will allow speech and language therapists to develop a better understanding of what causes speech problems for people with Parkinson's disease, and so target their therapy more effectively.

Secondly, there is currently no easy way for speech therapists to measure how much speech problems affect how people with Parkinson's disease talk in the real world, e.g. can they talk on the telephone to their grandchild, or in a crowded room to a stranger? So as one small part of this study we will check that a recently developed assessment measure from the USA will work in a British setting and with people with Parkinson's disease.

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1.2 Why was I chosen?

You have been invited to participate because you have been identified as a person who a person with Parkinson's disease known to you would be comfortable to have a conversation with. We would like conversation partners for two reasons. Firstly, we need comparison speech recordings to compare the recordings of the people with Parkinson's disease with. Secondly, people with Parkinson's disease may require assistance to complete the research questionnaires.

1.3 Do I have to take part?

No, it is up to you to decide. You have the right to choose whether or not you would like to participate in this study. We will describe the study in this information sheet, and we will then go through it with you before we start any of the research. If after this you decide you would like to take part, we will then ask you to sign a consent form to show you have agreed. You are free to withdraw at any time, without giving a reason.

1.4 Who can take part?

You are able to take part in this study as a conversation partner if you do not have Parkinson's disease and have not had any serious speech problems in the past. If you think you might like to take part, please return the reply slip in the pre-paid envelope provided.

1.5 What will I be expected to do if I take part?

Step 1:

A member of the research team will then telephone you to discuss the study,

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answer any questions you may have, and if you are still interested in taking part they will make an appointment to conduct the research.

Step 2:

The research appointment will be made at a time and day convenient to you and the person with Parkinson's disease. At the start of this appointment, the researcher will discuss the study with you to ensure you understand it and are happy to take part before we ask for consent. After you give consent, we expect the research procedures to take around 45 minutes. We are happy to visit you at a location convenient for both yourself and the person with Parkinson's disease or you can visit us at the Clinical Research and Trials Unit at the University of East Anglia. Any travel costs will be reimbursed.

Step 3: Video Recording

At the research appointment, once you and the person with Parkinson's disease have had sufficient time to discuss the study with us and give consent, the person with Parkinson's disease will be filmed reading 16 sentences that will be provided. Then we will ask them to repeat four of these sentences in a happy way and a sad way.

Step 4: Conversation Partner Video Recording

If you have agreed to take part in the research, we will ask you to read the sentences aloud, just as the person with Parkinson's disease has done. This acts as a comparison sample.

Then we will ask you to have a brief conversation with the person with

Parkinson's disease who has invited you to take part about a topic such as "a favourite day out".

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Step 4: Questionnaire for conversation partner

We will ask you to complete a short background information questionnaire, such as your age and how many years you have lived in Norfolk. Your name will not be used on any questionnaires.

Step 5:- Assisting the person with Parkinson's disease with completion of questionnaires

The person with Parkinson's disease may ask for your assistance to complete some questionnaires. These will help us understand factors that can affect their speech and language, and how they find talking in day-to-day activities. Their name will not be used on any questionnaires. The research team will have no access to medical records at any stage in the research. The questionnaires will cover the following topics:-

- Background information such as their age, how long they have lived in Norfolk, how many years they have had Parkinson's disease, whether they have any swallowing difficulties, what medication they are currently taking for Parkinson's
- Cognition (How well they can remember things, pay attention and problem solve)
- Mood (How you feel in yourself)
- How Parkinson's disease affects their everyday communication

We expect the questionnaires will take a total of around 30 minutes to

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Assessors

Two items in our study are to determine how understandable your speech and that of people with Parkinson's disease is to strangers, and whether they can determine your mood (happy, sad, neutral) from your tone of voice. To do this the video recordings of your speech will be viewed by students and staff who will assess it for intelligibility and mood. The assessors will be recruited from the University of East Anglia and will sign confidentiality agreements and be supervised by a member of the research team.

Speech Database

Although we have a plan of investigations we wish to complete on the video recording of you speaking, we recognise that we will not be able to do all possible investigations. We will have to select the most relevant ones for our particular study. We would like to create a secure database that will store the video recordings so that in the future other researchers can examine them. Additionally they would be a hugely valuable resource for speech therapy students to learn how to better understand people with Parkinson's disease who have difficulties with their speech.

Facial expressions are a key part of communication. However, obviously, you can be recognised from a picture or video of your face. So although your name would not be stored on the database, the video could allow you to be identified, so we have to treat this data with particular care. Only people that

have a legitimate reason to access the database would have access to it, e.g. lecturers, students, speech therapists, researchers.

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We are asking you separately for permission to store your recordings on the secure database. If you choose not to donate your recordings to the database, you are still eligible to take part in the main study.

1.5 Are there any risks to me?

We do not predict any risks by joining in this study.

1.6 Could taking part in the study do me some good?

The information we get from this study might help us better understand speech problems associated with Parkinson's disease. This may lead to better assessment and treatment of these speech problems in the future. We cannot promise that the findings of this study will be of direct benefit to you, but we hope that they will help people with Parkinson's disease in the future.

1.7 Expenses and payments

We will reimburse travel costs if the study visit does not take place in your home.

1.8 What if there is a problem?

Any complaint about the way you have been dealt with during the study will be addressed. The detailed information on this is given in Part 2.

1.9 Will my taking part in the study be kept confidential?

Yes. We will follow ethical and legal practice and all information about you will be handled in confidence. The details are included in Part 2.

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Part 2:

2.1 What will happen if I start being involved in the study but then don't want to carry on with the study?

You can stop taking part at any time and you do not have to give a reason. We will keep the data collected up to your withdrawal. This will not affect the care you receive.

2.2 What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions.

Mr Maxwell S. Barnish

Principal Investigator

Tel: 01603593300 (Monday to Friday office hours)

E-mail: m.barnish@uea.ac.uk

Dr Katherine Deane

Academic Supervisor

Tel: 01603 597047 (Monday to Friday office hours)

E-mail: k.deane@uea.ac.uk

In the event that something does go wrong and you are harmed during the research and this is due to someone's negligence then you may have grounds for a legal action for compensation against the University of East Anglia but you may have to pay your legal costs.

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2.3 Will my taking part in this study be kept confidential?

Yes. All information which is collected about you during the course of the research will be kept strictly confidential. All the information we obtain relating to you will be treated in the strictest confidence and stored in line with the Data Protection Act (1998). Only investigators from our team (who have formal legal duties of confidentiality) will have access to this information.

Your name will not be used and you will be identified only by an anonymous code. Questionnaires will be "linked anonymised". This means that we will use a numerical code rather than your name to identify your questionnaires. The link between names and codes will be stored in a locked filing cabinet in a locked room at the university and will only be accessed by members of the research team. When we write articles and give presentations about the project, and when we label your recordings, we will use this code, never your real name.

Data from this research will be stored securely for up to five years after the study is completed to allow us to fully analyse all of the data. After this time the data will be disposed of securely.

There are two circumstances where confidentiality may be broken – but only with your specific permission.

In the first instance, we may wish to present the video of your speech at presentations to research conferences, or as part of our research reports. As your face will be visible, you could be identified, so we will ask for specific permission to do this. If you do not want your video to be shared in this way it would be kept private and just used in the research and this would not prevent you joining in the rest of the research.

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In the second instance we want to ask you to allow us to preserve the video/audio recordings for the use of future research. If you agree, we will store the recordings in a secure controlled-access database such as the University College London (UCL) Human Communication Audio Visual Archive (CAVA) at UCL Library. We also ask you to give us permission to use these recordings for further analysis in future research projects and for teaching purposes. People who want to use your recordings will sign a licence agreement which means that they will have to respect your confidentiality, rights and dignity, and to use the data in a responsible way. They will only be able to use the data for bone fide research and teaching. If you choose to withdraw from the project before the end of the study, the recordings that have already been made will be kept in the archive. Your real name and address will not be kept in the archive.

2.4 What will happen to the results of the research study?

The results of the study will be used as part of Maxwell Barnish's PhD thesis which will be submitted to the University of East Anglia. We will send you a summary of the results of the study, publish the results in research journals to do with speech and health and send a summary of the project to Parkinson's UK. The results will also be presented at relevant conferences and shared with local professionals. In all of these publications you will not be identifiable unless you explicitly give consent for video recordings to be shown.

2.5 Who is organizing and funding the research?

This study is part of a three year PhD studentship project funded by the University of East Anglia. The Chief Investigator is PhD student, Mr Maxwell

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Barnish. Maxwell will work under the supervision of Dr Katherine Deane, Dr Simon Horton and Dr Zoe Butterfint.

2.6 Who has approved the study?

The study has been approved for funding by the Health and Social Sciences Research Institute, University of East Anglia. All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee to protect your safety, rights, wellbeing and dignity. The study has been reviewed and given a favourable opinion by NRES Committee East of England- Norfolk.

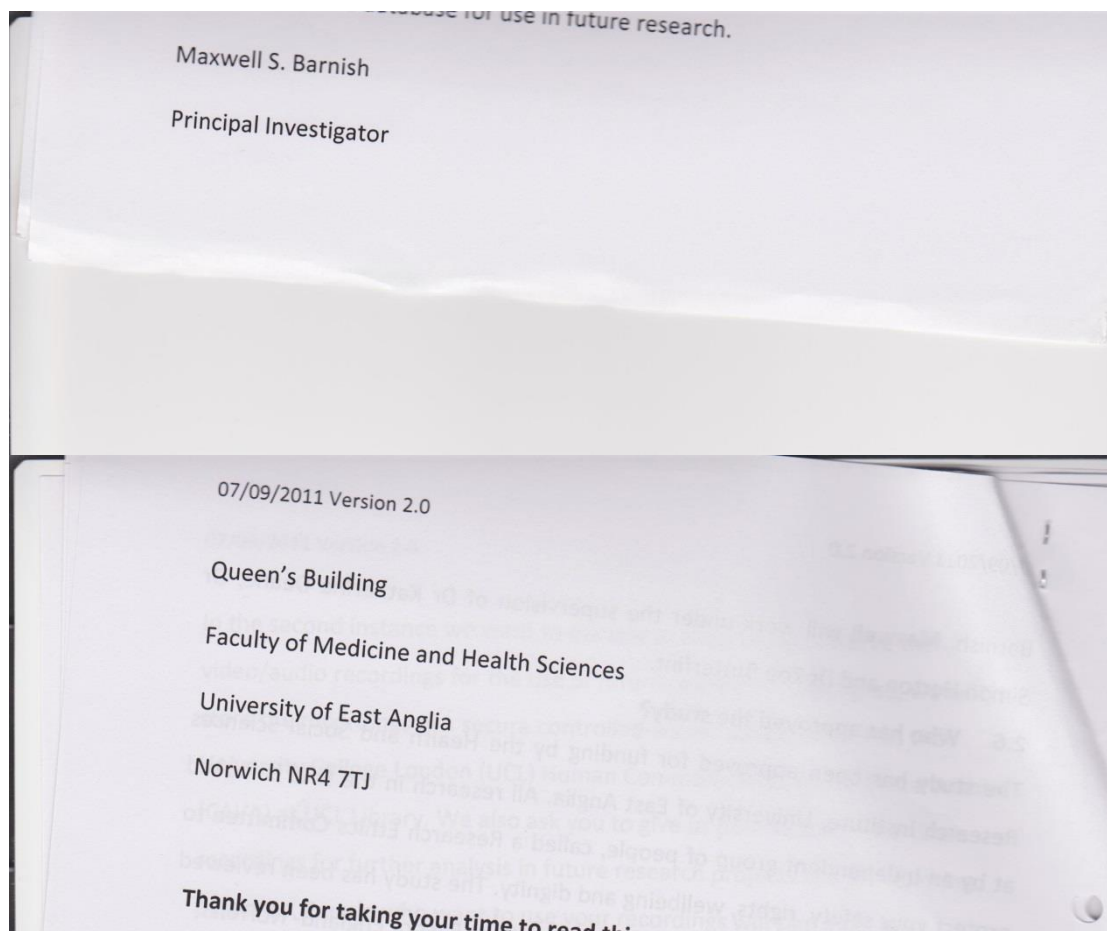
2.7 Contacts for Further Information

If you would like to discuss the study or are interested in taking part, please return the reply slip in the pre-paid envelope provided and a researcher will contact you.

If you would like information about taking part in research generally, please contact your GP or the Patient Advice and Liaison Service.

Monday to Friday, Office hours, Tel: 01603 289036, Email Address: PALS@nnuh.nhs.uk

If you decide to take part, thank you for participating in this research project. We would like to thank you for your contribution to research which aims to increase knowledge about factors affecting speech in Parkinson's disease and lead to developments in Speech and Language Therapy for Parkinson's disease. We are also very thankful to those who choose to donate their speech recordings to the database for use in future research.



Appendix 7: Neurology clinic invitation letter for people with Parkinson's disease



Factors affecting the speech of people with Parkinson's disease

Dear

We would like to invite you to take part in some research about things that affect the speech of people with Parkinson's disease. The study would involve a single meeting which would take place either in your home or at the University of East Anglia depending on your preference.

The study would involve:-

- Reading aloud some sentences and having a conversation with either a conversation partner (a relative, spouse or friend you are comfortable speaking to) or a member of the research team. This speech would be filmed by the research team member.
- The completion of some questionnaires about cognition (how well you can remember things, pay attention and problem solve), your mood (how you feel) and how Parkinson's disease affects your ability to communicate in everyday life.

We estimate that on average the speech recordings would take around 15 minutes and the questionnaires would take around 30 minutes. However, we recognize that people take different amounts of time to do these sorts of tasks. Before the study procedures start, you would have the opportunity to discuss the study with a member of the research team to ensure that you understand what you would be expected to do and are happy to take part.

For further information, please read the information leaflets. If you think that you might like to take part or would like to discuss the study with a member of the research team, please return the reply slip to the research

team in the pre-paid envelope provided and a member of the research team will telephone you. We would appreciate if you would give the conversation partner invitation letter and information sheet to an adult you would be willing to take part with you. This is to provide a comparison speech sample. However, you are also welcome to take part by yourself if you prefer.

Yours Sincerely

Dr Paul Worth

Consultant Neurologist

Norfolk and Norwich University Hospital

Colney Lane Norwich NR4 7UY



.....
 ✂

Reply Slip

I would like a member of the research team to telephone me to answer any questions I have and if I am still interested, to make an appointment to take part in the study. If you would like, your spouse, relative or friend can help with this telephone call.

Name:-

Telephone number:-

Day and time preference for the call:-

Please put this slip into the prepaid envelope and a member of the research team will telephone you shortly after receipt of the reply slip

Appendix 8: Medicine for the elderly clinic invitation letter for people with Parkinson's disease



Norfolk and Norwich University Hospitals 
NHS Foundation Trust



Factors affecting the speech of people with Parkinson's disease

Dear

We would like to invite you to take part in some research about things that affect the speech of people with Parkinson's disease. The study would involve a single meeting which would take place either in your home or at the University of East Anglia depending on your preference.

The study would involve:-

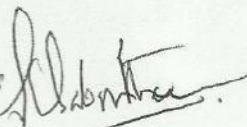
- Reading aloud some sentences and having a conversation with either a conversation partner (a relative, spouse or friend you are comfortable speaking to) or a member of the research team. This speech would be filmed by the research team member.
- The completion of some questionnaires about cognition (how well you can remember things, pay attention and problem solve), your mood (how you feel) and how Parkinson's disease affects your ability to communicate in everyday life.

We estimate that on average the speech recordings would take around 15 minutes and the questionnaires would take around 30 minutes. However, we recognize that people take different amounts of time to do these sorts of tasks. Before the study procedures start, you would have the opportunity to discuss the study with a member of the research team to ensure that you understand what you would be expected to do and are happy to take part.

For further information, please read the information leaflets. If you think that you might like to take part or would like to discuss the study with a member of the research team, please return the reply slip to the research team in the pre-paid envelope provided and a member of the research team will telephone you. We would appreciate if you would give the conversation partner invitation letter and information sheet to an adult you would be willing to take

part with you. This is to provide a comparison speech sample. However, you are also welcome to take part by yourself if you prefer.

Yours Sincerely

Drs  May Patel

Consultant in Medicine for the Elderly

Norfolk and Norwich University Hospital

Colney Lane Norwich NR4 7UY

..... ✂

Reply Slip

I would like a member of the research team to telephone me to answer any questions I have and if I am still interested, to make an appointment to take part in the study. If you would like, your spouse, relative or friend can help with this telephone call.

Name:-

Telephone number:-

Day and time preference for the call:-

Please put this slip into the prepaid envelope and a member of the research team will telephone you shortly after receipt of the reply slip

Appendix 9: Study consent form for people with Parkinson's disease



Project title: Factors affecting the speech of people with Parkinson's disease

Name of Researcher:

Part 1:- Consent to take part in the research study (information sheet version 2 dated 01/09/2011)

Please
initial
box

1. I confirm that I have read and understood the information sheet for the research project called 'Factors affecting the speech of people with Parkinson's disease'. ☐
2. I have had the opportunity to think about it and ask any questions. I am sure that I know enough about it to help me decide about taking part. ☐
3. I understand that I do not have to take part, it is my own choice. If I start taking part in the research I know that I can stop at any time. Any treatment I am having will not be affected in any way by my decision and I do not have to give a reason for stopping. ☐
4. I agree that the Principal Investigator (Maxwell Barnish) should tell my GP about me taking part in the study, and should tell my GP if there are any concerns about my health or welfare during the research. My participation in this study will be kept confidential and no-one except my GP will be informed. ☐

5. I agree to take part in the research study 'Factors affecting the speech of people with Parkinson's disease'.

☐

Part 2:- Additional consents. You can still take part in the study without agreeing to these

Please
initial
box

6. I agree for my audio and video recordings to be shown at research conferences. My name will not be supplied.

☐

7. I agree for my audio and video recordings to be included in research reports on this project. My name will not be supplied.

☐

Name of Participant

Date

Signature

Name of Person taking consent

Date

Signature

Participant Identification Number (researcher to complete): _____

When completed: 1 copy for participant, 1 copy for study master file, 1 (original) to be sent to GP.

Appendix 10: Study consent form for conversation partners

Project title: Factors affecting the speech of people with Parkinson's disease

Name of Researcher:

Part 1:- Consent to take part in the research study (information sheet version 2 dated 01/09/2011)

Please
initial
box

8. I confirm that I have read and understood the information sheet for the research project called 'Factors affecting the speech of people with Parkinson's disease'.

☐

9. I have had the opportunity to think about it and ask any questions. I am sure that I know enough about it to help me decide about taking part.

☐

10. I understand that my participation in this study will be kept confidential.

☐

11. I understand that I do not have to take part, it is my own choice. If I start taking part in the research I know that I can stop at any time.

☐

12. I agree to take part in the research study 'Factors affecting the speech of people with Parkinson's disease'.

☐

Part 2:- Additional consents. You can still take part in the study without agreeing to these

Please
initial
box

13. I agree for my audio and video recordings to be shown at research conferences. My name will not be supplied.

☐

14. I agree for my audio and video recordings to be included in research reports on this project. My name will not be supplied.

☐

Name of Participant

Date

Signature

Name of Person taking consent

Date

Signature

Participant Identification Number (researcher to complete): _____

When completed: 1 copy for participant, 1 copy for study master file.

Appendix 11: Database consent form for people with Parkinson's disease

05/09/2011 Version 1.0

12.12.1 Database Consent form for people with Parkinson's disease



Norfolk and Norwich University Hospitals NHS Foundation Trust



Project title: Factors affecting the speech of people with Parkinson's disease

Name of Researcher:

Consent to donate speech recordings to the secure controlled-access database (information sheet version 2 dated 01/09/2011)

Please
initial
box

1. I agree that my audiovisual recordings can be stored in a secure controlled-access database for future responsible use in research and teaching.

☐

2. I understand that my name will not be used in the database

☐

3. I understand that I don't have to donate my recordings in this way and that it is my choice

☐

_____	_____	_____
Name of participant	Date	Signature

_____	_____	_____
Name of person taking consent	Date	Signature

Participant Identification Number (Researcher to complete)

Appendix 12: Database consent form for conversation partners

05/09/2011 Version 1.0

12.12.2 Database Consent form for conversation partners



Project title: Factors affecting the speech of people with Parkinson's disease

Name of Researcher:

**Consent to donate speech recordings to the secure controlled-access database
(information sheet version 2 dated 01/09/2011)**

Please
initial
box

1. I agree that my audiovisual recordings can be stored in a secure controlled-access database for future responsible use in research and teaching.

☐

2. I understand that my name will not be used in the database

☐

3. I understand that I don't have to donate my recordings in this way and that it is my choice

☐

Name of participant Date Signature

Name of person taking consent Date Signature

Participant Identification Number (Researcher to complete)

Appendix 13: Baseline questionnaire for people with Parkinson's disease



Participant number:-

Questionnaire for people with Parkinson's

We need a few pieces of information from you for the study. All information will be stored anonymously. This should take around five minutes to complete.

- 1) What is your age?
- 2) How long have you lived in Norfolk?
- 3) How long have you had Parkinson's?
- 4) What is the highest educational qualification that you have?
Please tick

a) O Level, GCSE or equivalent ☐

a) A Level or
equivalent?..... ☐

b) Vocational training?..... ☐

c) Undergraduate degree?..... ☐

d) Postgraduate degree?..... ☐

- 5) Are you currently working? Please tick

a) Working..... ☐

b) Retired..... ☐

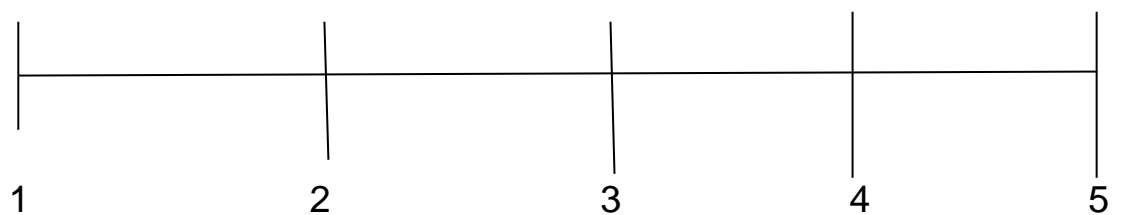
c) Unemployed..... ☐

d) In training or
education..... ☐

6) Which of the following categories best describes the job that you do or did prior to retirement? Please tick

- a) Manager..... ☐
- b) Professional..... ☐
- c) Technical/associate professional..... ☐
- d) Clerical support worker..... ☐
- e) Service and sales worker..... ☐
- f) Skilled agricultural, forestry and fishery worker..... ☐
- g) Craft and related trades worker..... ☐
- h) Plant and machine operator/assembler..... ☐
- i) Elementary occupation..... ☐
(E.g. cleaner, labourer, kitchen assistant)
- j) Armed forces occupations..... ☐

7) Please place a cross on the line to show how you rate your swallowing



1= Worst, 5= Best

8) Do you smoke? Please tick

- a) Currently..... ☐
- b) Never..... ☐
- c) In the past..... ☐

9) Have you had any Speech and Language Therapy for your Parkinson's? Please tick

- a) Yes.....☐
- b) No.....☐
- c) Don't know.....☐

10) Are you currently having Speech and Language Therapy?
Please tick

- a) Yes.....☐
- b) No.....☐
- c) On review.....☐
- d) Don't know.....☐

11) How many sessions have you had?

12) How often did you have sessions?

13) Do you feel Speech and Language Therapy helped?

- a) Yes.....☐
- b) No.....☐
- c) Don't know.....☐

14) Do you feel it focused enough on your everyday speaking?

- a) Yes.....☐
- b) No.....☐
- c) Don't know.....☐

15) Please write the name and address of your GP.

16) Please list the medication you are currently taking for Parkinson's

[illegible]

Appendix 14: Baseline questionnaire for conversation partners

Participant number:-



Questionnaire for conversation partners

We need a few pieces of information from you for the study. All information will be stored anonymously. This should take around five minutes to complete.

- 1) What is your age?
- 2) How long have you lived in Norfolk?
- 3) What is the highest educational qualification that you have?

Please tick

a) O Level, GCSE or equivalent..... ☐

b) A Level or equivalent?..... ☐

c) Vocational training?..... ☐

d) Undergraduate degree?..... ☐

e) Postgraduate degree?..... ☐

- 4) Are you currently working? Please tick

a) Working..... ☐

b) Retired..... ☐

c) Unemployed..... ☐

d) In training or
education..... ☐

- 5) Which of the following categories best describes the job that you do or did prior to retirement? Please tick

a) Manager..... ☐

b) Professional..... ☐

c) Technical/associate professional..... ☐

- d) Clerical support worker.....
- e) Service and sales worker.....
- f) Skilled agricultural, forestry and fishery worker.....
- g) Craft and related trades worker.....
- h) Plant and machine operator/assembler.....
- i) Elementary occupation.....
(E.g. cleaner, labourer, kitchen assistant)
- j) Armed forces occupations.....
- 6) Do you smoke? Please tick
- a) Currently.....
- b) Never.....
- c) In the past
- 7) Have you ever had problems with your speech requiring therapy?
- a) Yes.....
- b) No.....
- c) Don't know.....

Appendix 15: MoCA

MONTREAL COGNITIVE ASSESSMENT (MOCA)
Version 7.1 Original Version

NAME: _____
Education: _____ Sex: _____ Date of birth: _____ DATE: _____

VISUOSPATIAL / EXECUTIVE		Copy cube		Draw CLOCK (Ten past eleven) (3 points)		POINTS		
				<input type="checkbox"/> Contour <input type="checkbox"/> Numbers <input type="checkbox"/> Hands		___/5		
NAMING <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>								
MEMORY Read list of words, subject must repeat them. Do 2 trials, even if 1st trial is successful. Do a recall after 5 minutes.		FACE	VELVET	CHURCH	DAISY	RED	No points	
1st trial								
2nd trial								
ATTENTION Read list of digits (1 digit/sec). Subject has to repeat them in the forward order. Subject has to repeat them in the backward order.		<input type="checkbox"/> 2 1 8 5 4 <input type="checkbox"/> 7 4 2					___/2	
Read list of letters. The subject must tap with his hand at each letter A. No points if ≥ 2 errors.		<input type="checkbox"/> F B A C M N A A J K L B A F A K D E A A A J A M O F A A B					___/1	
Serial 7 subtraction starting at 100		<input type="checkbox"/> 93 4 or 5 correct subtractions: 3 pts, 2 or 3 correct: 2 pts, 1 correct: 1 pt, 0 correct: 0 pt	<input type="checkbox"/> 86 4 or 5 correct subtractions: 3 pts, 2 or 3 correct: 2 pts, 1 correct: 1 pt, 0 correct: 0 pt	<input type="checkbox"/> 79 4 or 5 correct subtractions: 3 pts, 2 or 3 correct: 2 pts, 1 correct: 1 pt, 0 correct: 0 pt	<input type="checkbox"/> 72 4 or 5 correct subtractions: 3 pts, 2 or 3 correct: 2 pts, 1 correct: 1 pt, 0 correct: 0 pt	<input type="checkbox"/> 65 4 or 5 correct subtractions: 3 pts, 2 or 3 correct: 2 pts, 1 correct: 1 pt, 0 correct: 0 pt	___/3	
LANGUAGE Repeat: I only know that John is the one to help today. The cat always hid under the couch when dogs were in the room.		<input type="checkbox"/> I only know that John is the one to help today. <input type="checkbox"/> The cat always hid under the couch when dogs were in the room.					___/2	
Fluency / Name maximum number of words in one minute that begin with the letter F		<input type="checkbox"/> _____ (N ≥ 11 words)					___/1	
ABSTRACTION Similarity between e.g. banana - orange - fruit		<input type="checkbox"/> train - bicycle <input type="checkbox"/> watch - ruler					___/2	
DELAYED RECALL Has to recall words WITH NO CUE		FACE	VELVET	CHURCH	DAISY	RED	Points for UNCUED recall only	
Category cue		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		
Optional Multiple choice cue								
ORIENTATION		<input type="checkbox"/> Date	<input type="checkbox"/> Month	<input type="checkbox"/> Year	<input type="checkbox"/> Day	<input type="checkbox"/> Place	<input type="checkbox"/> City	___/6
© Z. Nasreddine MD www.mocatest.org Normal ≥ 26 / 30		TOTAL _____ /30 Add 1 point if ≤ 12 yr edu						

Administered by: _____

Appendix 16: HADS

Permission to include HADS in the final post-examination copy of this thesis could not be obtained. Please consult Zigmond and Snaith (1983).

Appendix 17: CES

Our Vision
To provide every patient
with the care we want
for those we love the most

Norfolk and Norwich University Hospitals NHS
NHS Foundation Trust

UEA
University of East Anglia

Communicative Effectiveness Survey

In this survey we ask you to rate how effective **your speech** is in different communication situations. Please read each statement. The rate how effectively you communicate in that situation. If your speech is very effective, mark the 4. If your speech does not allow you to communicate at all in a situation, mark the 1. Feel free to use any number on the scale.

	1 Not at all effective	2	3	4 Very effective
1) Having a conversation with a family member or friends at home				✓
2) Participating in conversation with strangers in a quiet place			✓	
3) Conversing with a familiar person over the telephone				✓
4) Conversing with a stranger over the telephone		✓		
5) Being part of a conversation in a noisy environment (social gathering)			✓	

(24)

	1 Not at all effective	2	3	4 Very effective
6) Speaking to a friend when you are emotionally upset or you are angry				✓
7) Having a conversation while travelling in a car			✓	
8) Having a conversation with someone at a distance (across a room).	✓			
1) Having a conversation with a family member or friends at home				
2) Participating in conversation with strangers in a quiet place				
3) Conversing with a familiar person over the telephone				
4) Conversing with a stranger over the telephone				
5) Being part of a conversation				

Appendix 18: CPIB

Items that are in CPIB10 are indicated in bold



Communicative Participation Item Bank

“The following questions describe a variety of situations in which you might need to speak to others. For each question, please mark how much your condition interferes with your participation in that situation. By “condition” we mean ALL issues that may affect how you communicate in these situations including speech conditions, any other health conditions, or features of the environment. If your speech varies, think about an AVERAGE day for your speech – not your best or your worst days.”

How much does your condition interfere with:-

	Not at all	A little	Quite a bit	Very much
1) Giving personal advice to help a family member or friend?				
2) Answering questions from a doctor or health care provider who you know?				
3) Answering questions in a conversation?				
4) Communicating with others where and when you choose?				
5) Talking to a shop assistant who is in a hurry?				
6) Talking with a shop assistant about a problem with a bill or purchase?				
7) Comforting a friend or family member?				

8) Communicating when you are out and about in your community (e.g. errands; appointments)?				
9) Having a conversation while riding in a car?				
	Not at all	A little	Quite a bit	Very much
10) Giving someone DETAILED information?				
11) Talking with people you do NOT know?				
12) Communicating during an emergency?				
13) Talking about an emotional issue with family or friends?				
14) Sharing personal feelings with people who are close to you?				
15) Saying something to get someone's attention?				
16) Getting your turn in a fast-moving conversation?				
17) Giving directions to someone who is lost and has asked you for help?				
18) Greeting someone you know at a social gathering?				
19) Communicating at home?				
20) If you were with someone you knew and needed to ask them for help right away?				
21) With asking for help from a stranger?				
22) Communicating in a large group of people?				
23) Having a long conversation with someone you knew about a book,				

movie, show or sports event?				
24) Talking with important people in your life about your wishes regarding long-term planning?				
	Not at all	A little	Quite a bit	Very much
25) Negotiating?				
26) Making new acquaintances?				
27) Bringing up a new topic in casual conversation?				
28) Having a conversation in a noisy place?				
29) Sharing your opinion with family and friends?				
30) Ordering a meal in a restaurant?				
31) Trying to get a friend or family member to see a different point of view?				
32) Making a phone call to get information?				
33) Taking a phone message?				
34) Talking with friends or family about something you are planning to do with them?				
35) Visiting with others in a public place (e.g. park, restaurant, sports activity)?				
36) Communicating when you need to say something quickly?				
37) Having a conversation about a serious topic?				
38) Communicating in a small group of people?				
39) Making small talk?				
40) Communicating at social gatherings				

where you know most of the people?				
41) Starting a conversation with someone you know?				
	Not at all	A little	Quite a bit	Very much
42) Talking with people you know?				
43) Expressing thanks or appreciation?				
44) Making comments to family or friends about a TV show or movie you are watching together?				
45) Getting your point across when you are upset?				
46) Making a witty or funny comment in a conversation?				

This scale has been developed in the USA. We would appreciate if you could tell us whether there were any difficulties with the language which affected understanding. If so which questions were particularly difficult to understand?

Appendix 19: General practitioner information leaflet regarding their patient's depression



GP Information Leaflet regarding their patient's depression

Dear Dr

When your patient completed the Hospital Anxiety and Depression Assessment Scale (HADS) as part of the research study Factors affecting the speech of people with Parkinson's disease, their score indicated that they may be suffering from depression.

Your patient's HADS score indicates mild moderate/severe depression. (delete as appropriate)

We informed them of this fact immediately and gave them an information sheet regarding the management of depression in line with NICE guidance (2009), a copy of which is enclosed with this letter. They are aware that we are sending this letter to you informing you of our concerns regarding their mental wellbeing.

If you require any further information, please contact Mr Maxwell Barnish, the Principal Investigator on m.barnish@uea.ac.uk or 01603593300

Yours sincerely

Maxwell Barnish

Principal Investigator

Queen's Building

Faculty of Medicine and Health Sciences

University of East Anglia

Norwich NR4 7TJ

Appendix 20: Mild depression information leaflet



Mild Depression Information Leaflet

Dear

When you completed the Hospital Anxiety and Depression Assessment Scale as part of research study Factors affecting the speech of people with Parkinson's disease, your score indicated that you may be suffering from mild depression. We will send a letter to your GP also giving them this information.

Depression is a common condition. About one in six people will experience depression during their lifetime. (NHS Direct 2010)

It can affect anyone: men and women, young and old. Although more women than men seek treatment for depression, this does not necessarily mean that men are less likely to get depressed. It could mean they are more reluctant to seek help.

Sometimes there is a trigger for depression. Life-changing events, such as bereavement, having a baby or losing your job, can all cause depression. But you can also become depressed for no obvious reason.

What is the difference between feeling low and depression?

Feeling low or down is something we all experience from time to time. It's a common response to sad or difficult events and situations.

Depression is when these feelings are persistent or so strong that they prevent you from doing the things you would normally do.

What are the symptoms of depression?

Symptoms of depression include lasting feelings of sadness, losing interest in the things you used to enjoy, feeling constantly tired, having difficulty getting to sleep, loss of appetite and feeling life is not worth living.

Self help strategies

Mild depression, in particular, is more likely to respond to self-help. There are several things you can do yourself that might help you cope better with depression or prevent another episode of depression. These include exercising on a regular basis and finding a support group. Sources of good quality self-help information are given at the bottom of this sheet.

If you're still feeling down after a couple of weeks, please talk to your GP or call NHS Direct (0845 4647).

Good Quality Information Sources

NHS Direct

NHS Direct is here to make a difference to the lives of people in England, 24 hours a day, 365 days a year. We're here for you whenever you have health worries and we have the knowledge and experience to give you real help and reassurance.

Tel: 0845 4647

Web:

<http://www.nhs.uk/livewell/depression/pages/depressionhome.aspx>

BBC Health

Web:

http://www.bbc.co.uk/health/emotional_health/mental_health/disorders_depression.shtml

SANE: Mental Health Charity

SANeline and SANEmail offer emotional support and information to those experiencing mental health problems, their families and carers.

Contact SANeline / SANEmail:

1st Floor Cityside House, 40 Adler Street, London, E1 1EE

Helpline: 0845 767 8000, fax: 020 7375 2162

email: sanemail@sane.org.uk

web: www.sane.org.uk

Web: <http://www.sane.org.uk/AboutMentalIllness/Depression>

MIND: Mental Health Charity

Mind*info***line**

We are able to provide information on a range of topics including types of mental distress, where to get help, drug and alternative treatments and advocacy. We are able to provide details of help and support for people in their own area.

Contact Mind***info***line:

Mind***info***line

PO Box 277

Manchester

M60 3XN

Tel: 0845 766 0163

email: info@mind.org.uk

Web:

http://www.mind.org.uk/help/diagnoses_and_conditions/depression

Appendix 21: Moderate- to- severe depression information leaflet



Moderate to Severe Depression Information Leaflet

Dear

When you completed the Hospital Anxiety and Depression Assessment Scale as part of the study Factors affecting the speech of people with Parkinson's disease, your score indicated that you may be suffering from depression. We will send a letter to your GP also giving them this information.

Depression is a common condition. About one in six people will experience depression during their lifetime. (NHS Direct 2010)

It can affect anyone: men and women, young and old. Although more women than men seek treatment for depression, this does not necessarily mean that men are less likely to get depressed. It could mean they are more reluctant to seek help.

Sometimes there is a trigger for depression. Life-changing events, such as bereavement, having a baby or losing your job, can all cause depression. But you can also become depressed for no obvious reason.

What is the difference between feeling low and depression?

Feeling low or down is something we all experience from time to time. It's a common response to sad or difficult events and situations.

Depression is when these feelings are persistent or so strong that they prevent you from doing the things you would normally do.

What are the symptoms of depression?

Symptoms of depression include lasting feelings of sadness, losing interest in the things you used to enjoy, feeling constantly tired, having difficulty getting to sleep, loss of appetite and feeling life is not worth living.

When to seek medical help

The assessment you have completed indicates that you are depressed and should talk to your GP immediately so that you can decide what are the best options to help you deal with this.

If you start feeling like you can't cope, life is becoming very difficult or your life isn't worth living, get help straight away. These are signs that you need to talk to someone.

Either contact your GP or call NHS Direct (0845 4647). You can also contact help lines such as Samaritans (08457 90 90 90) for confidential, non-judgemental emotional support.

What treatment is available for depression?

Depression is mostly treated in primary care. This means that GPs generally help you choose the most appropriate treatment and manage your care. People with depression are now offered a wide range of treatment options including:

- Antidepressants
- Psychological therapies such as cognitive behavioural therapy (CBT) and counselling.
- Guided self-help, which could, for example, mean your GP gives you a list of recommended self-help books.
- Advice on changes you can make to your lifestyle that will help you.

“The type of treatment or combination of treatments that suits you will depend on your preferences, your general health and on how severe your depression is,” says Dr Alan Cohen, a GP with a special interest in mental health.

Many people with moderate or severe depression wait a long time before seeking help. Dr Cohen’s advice is to seek an early diagnosis. “There is a range of options available to treat depression. With the right treatment most people make a full recovery. The sooner you get help, the sooner you’ll feel better.”

Appendix 22: Research ethics approval



National Research Ethics Service

NRES Committee East of England - Norfolk

Victoria House
Capital Park
Fulbourn
Cambridge
CB21 5XB

Telephone: 01223 597597
Facsimile: 01223 597645

09 September 2011 (Reissued 14 September 2011 with addition to list of approved documents in bold)

Mr Maxwell S Barnish
PhD Student
University of East Anglia
Room 0.27, Queen's Building
University of East Anglia
Norwich
NR4 7TJ

Dear Mr Barnish

Study title: An investigation of the relationships between speech and communication characteristics and cognitive status in people with Parkinson's disease.
REC reference: 11/EE/0274

Thank you for your letter of 07 September 2011, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair in consultation with Liz Lund.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Poster	1	05 September 2011
Evidence of insurance or indemnity: Letter from UEA		29 June 2011
Evidence of insurance or indemnity: Zurich Municipal Certificate		25 May 2011
Evidence of insurance or indemnity: Zurich Municipal Certificate		16 June 2010
GP/Consultant Information Sheets: Depression Information Leaflet for GPs	2.0	07 September 2011
GP/Consultant Information Sheets: For GP of the person with Parkinson's Disease	1.0	06 June 2011
Investigator CV: Maxwell Scott Barnish		09 June 2011
Letter of invitation to participant: People with Parkinson's disease (from Speech and Language Therapy),	1.0	06 June 2011
Letter of invitation to participant: People with Parkinson's disease (from Neurology),	1.0	06 June 2011
Letter of invitation to participant: People with Parkinson's disease (from Medicine for the Elderly)	1.0	06 June 2011
Letter of invitation to participant: Conversation partner (from Speech and Language Therapy)	1.0	06 June 2011
Letter of invitation to participant: Conversation partner (from Neurology)	1.0	06 June 2011
Letter of invitation to participant: Conversation partner (from Medicine for the Elderly)	1.0	06 June 2011
Letter of invitation to participant: People with Parkinson's disease	2.0	05 September 2011
Other: Depression Information Leaflet: Mild depression	1	06 June 2011
Depression Information Leaflet: Moderate to severe	1	06 June 2011
Other: List of example sentences	1.0	06 June 2011
Other: Academic Supervisor CV: Katherine Deane		11 March 2011
Other: Academic Supervisor CV: Simon Horton		09 May 2011
Other: Academic Supervisor CV: Zoe Butterfint		09 May 2011
Participant Consent Form: Database Consent form for people with Parkinson's disease	1.0	05 September 2011
Participant Consent Form: Database Consent form for conversation partners	1.0	05 September 2011
Participant Consent Form: People with Parkinson's disease	2.0	05 September 2011
Participant Consent Form: Conversation partner	2.0	05 September 2011

Participant Information Sheet: Conversation partner	2.0	07 September 2011
Participant Information Sheet: Assessor Information Sheet	2.0	06 September 2011
Protocol	2.0	07 September 2011
Questionnaire: Montreal Cognitive Assessment		
Questionnaire: Hospital Anxiety and Depression Scale		
Questionnaire: Communication Participation Item Bank		
Questionnaire: Communicative effectiveness Survey		
REC application	Submission code 73617/22756 7/149	
Response to Request for Further Information		07 September 2011

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

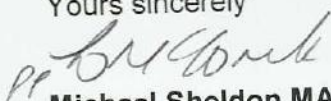
Further information is available at National Research Ethics Service website > After Review

11/EE/0274

Please quote this number on all correspondence

With the Committee's best wishes for the success of this project

Yours sincerely



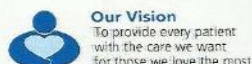
Michael Sheldon MA, PhD

Chair

Email: lynda.mccormack@eoe.nhs.uk

This Research Ethics Committee is an advisory committee to East of England Strategic Health Authority
The National Research Ethics Service (NRES) represents the NRES Directorate within

Appendix 23: Research and development approval



Norfolk and Norwich University Hospitals **NHS**
NHS Foundation Trust

Mr Maxwell Scott Barnish
University of East Anglia
Room 0.27
Queen's Building
Norwich
Norfolk
NR4 7TJ
United Kingdom

Research & Development Office
Level 3 East
Norfolk & Norwich University Hospitals NHS Foundation Trust
Colney Lane
Norwich
NR4 7UY

direct dial: 01603 287806
direct fax: 01603 289800
e-mail: rdoffice@nnuh.nhs.uk
website: www.nnuh.nhs.uk

11 November 2011

Dear Mr Maxwell Scott Barnish

Re: R&D Reference Number: 2011NEUR05S (80-06-11)

Project Title: An investigation of the relationships between speech and communication characteristics and cognitive status in people with Parkinson's disease.

I am pleased to inform you that the above project has been given full NHS permission for research at Norfolk & Norwich University Hospitals NHS Foundation Trust.

This NHS permission for research has been granted on the basis described in the application form, protocol and supporting documentation. The documents reviewed were:

Document	Version	Date
Protocol	2.0	07 September 2011
Poster for assessors	1	05 September 2011
Depression Information Leaflet for GPs	2	07 September 2011
Invitation letter to participant: People with PD (from Speech and Language Therapy)	1.0	06 June 2011
Invitation letter to participant: People with PD (from Neurology)	1.0	06 June 2011
Invitation letter to participant: People with PD (from Medicine for Elderly)	1.0	06 June 2011
Invitation letter to participant: Conversation partner (from Speech and Language Therapy)	1.0	06 June 2011
Invitation letter to participant: Conversation partner (from Neurology)	1.0	06 June 2011
Invitation letter to participant: Conversation partner (from Medicine for Elderly)	1.0	06 June 2011
Depression Information leaflet – Mild depression	1.0	06 June 2011
Depression Information leaflet – Moderate to severe depression	1.0	06 June 2011
List of example sentences	1.0	06 June 2011
Participant consent form – Database consent form for people with Parkinson's disease	1.0	05 September 2011
Participant consent form – Database consent form for conversation partners	1.0	05 September 2011
Participant consent form – People with Parkinson's disease	2.0	05 September 2011
Participant consent form – Conversation partner	2.0	05 September 2011
Participant consent form – Assessor confidentiality agreement	2.0	02 September 2011

Norfolk & Norwich University Hospitals NHS Foundation Trust

Participant information sheet : People with Parkinson's disease	2.0	07 September 2011
Participant information sheet : Conversation partner	2.0	07 September 2011
Participant information sheet : Assessor Information Sheet	2.0	06 September 2011
Questionnaire : Montreal Cognitive Assessment		
Questionnaire: Hospital Anxiety and Depression Scale		
Questionnaire: Communicative participation item bank		
Questionnaire: Communicative effectiveness survey		
GP Information Letter: For GP of the person with Parkinson's disease	2.0	05 September 2011

I have enclosed two copies of the Standard Terms and Conditions of Approval. Please sign both copies returning one copy to the Research Governance office at the above address and keeping the other in your study file. Failure to return the standard terms and conditions may affect the conditions of approval.

Please note, under the agreed Standard Terms and Conditions of Approval you must inform the R&D department of any proposed changes to this study and submit annual progress reports to the R&D department.

If you have any queries regarding this or any other project please contact Seema Gopinath, Research Facilitator, at the above address. Please note, the reference number for this study is **2011NEUR05S (80-06-11)** and this should be quoted on all correspondence.

Yours sincerely



Krishna Sethia
Clinical Director

Enc

Carbon Copy: Dr Paul Worth

Appendix 24: Letter of access for research



Our Vision
To provide every patient
with the care we want
for those we love the most

Norfolk and Norwich University Hospitals **NHS**
NHS Foundation Trust

Mr Maxwell Barnish
University of East Anglia
Room 0.27
Queen's Building
Norwich, Norfolk
NR4 7TJ

11th November 2011

Dear Mr Barnish

Re: 2011NEUR05S (80-06-11) An investigation of the relationships between speech and communication characteristics and cognitive status in people with Parkinson's disease.

Letter of access for research

This letter confirms your right of access to conduct research through Norfolk & Norwich University Hospitals NHS Foundation Trust for the purpose and on the terms and conditions set out below. This right of access commences on 11th November 2011 and ends on 30th September 2013 unless terminated earlier in accordance with the clauses below.

You have a right of access to conduct such research as confirmed in writing in the letter of permission for research from this NHS organisation. Please note that you cannot start the research until the Principal Investigator for the research project has received a letter from us giving permission to conduct the project.

The information supplied about your role in research at Norfolk & Norwich University Hospitals NHS Foundation Trust has been reviewed and you do not require an honorary research contract with this NHS organisation. We are satisfied that such pre-engagement checks as we consider necessary have been carried out.

You are considered to be a legal visitor to Norfolk & Norwich University Hospitals NHS Foundation Trust premises. You are not entitled to any form of payment or access to other benefits provided by this NHS organisation to employees and this letter does not give rise to any other relationship between you and this NHS organisation, in particular that of an employee.

While undertaking research through Norfolk & Norwich University Hospitals NHS Foundation Trust, you will remain accountable to University of East Anglia, but you are required to follow the reasonable instructions of Dr Paul Worth, Consultant in this NHS organisation or those given on her/his behalf in relation to the terms of this right of access.

Where any third party claim is made, whether or not legal proceedings are issued, arising out of or in connection with your right of access, you are required to co-operate fully with any investigation by this NHS organisation in connection with any such claim and to give all such assistance as may reasonably be required regarding the conduct of any legal proceedings.

You must act in accordance with Norfolk & Norwich University Hospitals NHS Foundation Trust policies and procedures, which are available to you upon request, and the Research Governance Framework.

You are required to co-operate with Norfolk & Norwich University Hospitals NHS Foundation

Research & Development Office
Level 3 East
Norfolk & Norwich University Hospitals NHS Foundation Trust
Colney Lane
Norwich
NR4 7UY

direct dial: 01603 287806
direct fax: 01603 289800
e-mail: rdoffice@nnuh.nhs.uk
website: www.nnuh.nhs.uk

Trust in discharging its duties under the Health and Safety at Work etc Act 1974 and other health and safety legislation and to take reasonable care for the health and safety of yourself and others while on Norfolk & Norwich University Hospitals NHS Foundation Trust premises. You must observe the same standards of care and propriety in dealing with patients, staff, visitors, equipment and premises as is expected of any other contract holder and you must act appropriately, responsibly and professionally at all times.

You are required to ensure that all information regarding patients or staff remains secure and *strictly confidential* at all times. You must ensure that you understand and comply with the requirements of the NHS Confidentiality Code of Practice (<http://www.dh.gov.uk/assetRoot/04/06/92/54/04069254.pdf>) and the Data Protection Act 1998. Furthermore you should be aware that under the Act, unauthorised disclosure of information is an offence and such disclosures may lead to prosecution.

You should ensure that, where you are issued with an identity or security card, a bleep number, email or library account, keys or protective clothing, these are returned upon termination of this arrangement. Please also ensure that while on the premises you wear your ID badge at all times, or are able to prove your identity if challenged. Please note that this NHS organisation accepts no responsibility for damage to or loss of personal property.

We may terminate your right to attend at any time either by giving seven days' written notice to you or immediately without any notice if you are in breach of any of the terms or conditions described in this letter or if you commit any act that we reasonably consider to amount to serious misconduct or to be disruptive and/or prejudicial to the interests and/or business of this NHS organisation or if you are convicted of any criminal offence.

Your substantive employer is responsible for your conduct during this research project and may in the circumstances described above instigate disciplinary action against you.

Norfolk & Norwich University Hospitals NHS Foundation Trust will not indemnify you against any liability incurred as a result of any breach of confidentiality or breach of the Data Protection Act 1998. Any breach of the Data Protection Act 1998 may result in legal action against you and/or your substantive employer.

If your current role or involvement in research changes, or any of the information provided in your Research Passport changes, you must inform your employer through their normal procedures. You must also inform your nominated manager in this NHS organisation.

Yours sincerely



Kath Andrews
R&D Manager

cc: HR department of the substantive employer

Appendix 25: Ethics approval for CPIB amendment



Health Research Authority

NRES Committee East of England - Norfolk

Victoria House
Capital Park
Fulbourn
Cambridge
CB21 5XB

Tel: 01223 596906

22 December 2011

Mr Maxwell S Barnish
PhD Student
University of East Anglia
Room 0.27, Queen's Building
University of East Anglia
Norwich
NR4 7TJ

Dear Mr Barnish

Study title: An investigation of the relationships between speech and communication characteristics and cognitive status in people with Parkinson's disease.

REC reference: 11/EE/0274

Protocol number: N/A

Amendment number: Amendment #1 Substantial

Amendment date: 02 December 2011

Amendment details: The inclusion of an assessment scale in the research study. The assessment has been approved by the Steering Committee lay adviser. No changes will need to be made to the appointment duration, and therefore there are no changes to the PIS and consent forms.

The above amendment was reviewed by the Sub-Committee in correspondence.

Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Questionnaire: Communicative Participation Item Bank	Version 2.0	02 December 2011
Protocol	Version 3.0	02 December 2011
Notice of Substantial Amendment (non-CTIMPs)	Amendment #1 Substantial	02 December 2011

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

R&D approval

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

11/EE/0274:

Please quote this number on all correspondence

Yours sincerely

H. Kaur

PP

Michael Sheldon MA, PhD
Chair

E-mail: Recofficetemp@eoe.nhs.uk

Enclosures:

List of names and professions of members who took part in the review

Ms Tracy Moulton
Research Contracts Manager
University of East Anglia
Norwich
NR4 7TJ

Ms Kathryn Andrews
Norfolk and Norwich Hospitals NHS Trust
R&D Office, Level 3, East Block
Colney Lane
Norwich
NR4 7UY

NRES Committee East of England - Norfolk


Attendance at Sub-Committee of the REC meeting on 20 December 2011

<i>Name</i>	<i>Profession</i>	<i>Capacity</i>
Mr Ron Driver	Lecturer/Statistician	Expert
Michael Sheldon MA, PhD	Retired Clinical Psychologist	Lay


Also in attendance:

<i>Name</i>	<i>Position (or reason for attending)</i>
Ms Har Hari Kaur	Assistant Co-ordinator

Appendix 26: Research and development approval for CPIB amendment



Our Vision
To provide every patient
with the care we want
for those we love the most

Norfolk and Norwich University Hospitals 

NHS Foundation Trust

Mr Maxwell Scott Barnish
University of East Anglia
Room 0.27
Queen's Building
Norwich
Norfolk
NR4 7TJ

January
04 December 2012

Research & Development Office
Level 3 East
Norfolk & Norwich University Hospitals NHS Foundation Trust
Colney Lane
Norwich
NR4 7UY

direct dial: 01603 287806
direct fax: 01603 289800
e-mail: rdoffice@nnuh.nhs.uk
website: www.nnuh.nhs.uk

Dear Mr Barnish

Re: R&D Reference Number: 2011NEUR05S (80-06-11)
Project Title: An investigation of the relationships between speech and communication characteristics and cognitive status in people with Parkinson's disease.

Thank you for your correspondence dated 05 December 2011 regarding amendment 1 for the above study. It was noted that the amendment has already received a favourable opinion from the NRES Committee of East England - Norfolk.

Following review of the documentation I am pleased to inform you that Trust approval has been given for these changes.

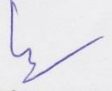
The documents reviewed and approved are as follows;

Document	Version	Date
Questionnaire: Communicative Participation Item Bank	2.0	02 December 2011
Protocol	3.0	02 December 2011

If you have any queries regarding this or any other project please contact Seema Gopinath, Research Facilitator, at the above address. Please note, the reference number for this study is **2011NEUR05S (80-06-11)** and this should be quoted on all correspondence.

If you have any queries regarding this or any other project please contact Seema Gopinath, Research Facilitator, at the above address. Please note, the reference number for this study is **2011NEUR05S (80-06-11)** and this should be quoted on all correspondence.

Yours sincerely



Professor Krishna Sethia
Medical Director

Carbon Copy: Dr Paul Worth

Appendix 27: Latest approved protocol



Study title: An investigation of the relationships between speech and communication characteristics and cognitive status in people with Parkinson's disease

Short title: Factors affecting the speech of people with Parkinson's disease

Authors: Maxwell Scott Barnish₁, Katherine Deane₁, Simon Horton₂ and Zoe Butterfint₂

₁ School of Nursing Sciences, Faculty of Medicine and Health Sciences, University of East Anglia, UK

₂ School of Allied Health Professions, Faculty of Medicine and Health Sciences, University of East Anglia, UK

Principal investigator:	<p>Maxwell Scott Barnish MA MSc</p> <p>PhD Student, School of Nursing Sciences, Faculty of Medicine and Health Sciences, University of East Anglia, UK</p> <p>Email: m.barnish@uea.ac.uk</p>
Primary academic supervisor:	<p>Dr Katherine Deane BSc PhD</p> <p>Senior Lecturer in Research Related to Nursing</p> <p>& School of Nursing Sciences Director of Learning and Teaching Quality (for Post-Graduate Research)</p> <p>School of Nursing Sciences, Faculty of Medicine and Health Sciences, University of East Anglia, UK</p> <p>Email: k.deane@uea.ac.uk</p>
Sponsor:	University of East Anglia

	Contact: Miss Tracy Moulton, Research Contracts Manager Email: t.moulton@uea.ac.uk
Funder:	University of East Anglia PhD Studentship
Signatures:	<p>Mr M. Barnish Date.....</p> <p>Dr K. Deane..... Date.....</p> <p>Miss T. Moulton..... Date.....</p>

1 SYNOPSIS

Study Title	An investigation of the relationships between speech and communication characteristics and cognitive status in people with Parkinson's disease
Study Design	A cross-sectional case-controlled observational study
Study Participants	Adults with idiopathic Parkinson's disease and communication difficulties Conversation partners of people with Parkinson's disease
Planned Sample Size	40 people with Parkinson's disease and their conversation partners.
Planned study site(s)	The study population comprises people with Parkinson's disease from the Norwich Community Hospital and Norwich and Norfolk University Hospital. People with Parkinson's disease will either come to the NHS Clinical Research & Trials Unit Norwich or be visited in their own home.

Follow-up duration	Two weeks
Planned Study Period	Two years
Primary Objectives	<ul style="list-style-type: none"> • To assess the impact of cognitive impairment on speech, language and communication in Parkinson's disease
Secondary Objectives	<ul style="list-style-type: none"> • To assess the relationship between cognitive impairments and communicative participation • To assess the relationships between cognitive impairments and language, the acoustic quality and intelligibility of speech • To characterize the acoustic qualities of both conversation partners' and people with Parkinson's disease' speech and investigate which acoustic properties contribute most to intelligibility. • To assess the impact of anxiety, depression and demographic factors on cognition, speech acoustics, intelligibility and communicative participation • To validate in the UK the Communicative Participation Item Bank including test-retest reliability and validity assessment using the Communicative Effectiveness Survey • To create a database of audiovisual recordings of the speech of people with Parkinson's disease and their conversation partners for the benefit of future research and training of student Speech and Language Therapists
Measures	<p>Montreal Cognitive Assessment (MoCA)</p> <p>Hospital Anxiety and Depression Scale (HADS)</p> <p>Communicative Participation Item Bank</p> <p>Communicative Effectiveness Survey (CES)</p>

2 ABBREVIATIONS

AssIDS	Assessment of Intelligibility of Dysarthric Speech
CAVA	Communication Audio Visual Archive
CES	Communicative Effectiveness Survey
CRF	Case report form
DWP	Department for Work and Pensions
GCP	Good Clinical Practice
GP	General practitioner
GPDS	Global Parkinson's Disease Survey
HADS	Hospital Anxiety And Depression Scale
ICF	International Classification of Functioning
MoCA	Montreal Cognitive Assessment

NCH	Norwich Community Hospital
NHS	National Health Service
NICE	National Institute of Clinical Excellence
NNUH	Norfolk and Norwich University Hospital
ONS	Office of National Statistics
PD	Parkinson's disease
PI	Principal Investigator
PIP	Participant information pack
R&D	Research and development
SC	Steering Committee
SLT	Speech and language therapy/therapist
SMF	Study Master File
SMG	Study Management Group
UCL	University College London
UEA	University of East Anglia
UK	United Kingdom
USA	United States of America
WHO	World Health Organization

3 BACKGROUND

3.1 Introduction to Parkinson's disease

Parkinson's disease is the second most prevalent neurological disability in the United Kingdom (UK) affecting around 1000 per 100,000 of the over 60s population (Department for Work and Pensions- Prevalence of Parkinson's disease). In light of the ageing demographic of the UK population (Office of National Statistics 2008), Parkinson's disease (PD) is a major healthcare challenge of the future. It is believed to result from the death of cells in the midbrain which produce the chemical dopamine (Soukup & Adams 1996). This loss reduces the efficiency of transmission of brain signals (McPherson & Cummings 1996). Originally described as a movement disorder (Parkinson 1817), PD is now recognized as a complex condition associated with a wide range of movement, psychological, cognitive and communicative problems. These symptoms significantly impinge upon Quality of Life (Global Parkinson's disease Survey 2002).

3.2 Cognition and communication in Parkinson's disease

Between 24% and 36% of people newly diagnosed with Parkinson's disease are believed to have some degree of cognitive impairment without dementia (Muslimović 2005, Foltynie 2004). This compares with 17% of the normal elderly population (Graham 1997). A wide range of cognitive impairments have been identified including planning, problem-solving, concentration and memory (Owen 1992). Over half of people with Parkinson's disease report dissatisfaction with their speech and communication (Miller 2008b).

Studies have demonstrated a role for cognitive impairment in reduced performance of people with Parkinson's disease on a wide range of language tasks. For example, people with Parkinson's disease have been shown to have difficulty understanding complicated grammatical structures (Grossman 1992, Terzi 2005). It has been suggested that this results from a range of cognitive impairments including working memory and slowed information processing speed (Grossman 2002). Impaired use (Darkins 1988) and perception (Schröder 2006) of emotion in speech and difficulty understanding non-literal language such as irony (Monetta 2009) have also been shown.

However there has been a lack of studies examining the relationship between cognitive impairments and everyday communication in Parkinson's disease. Instead, the vast majority of studies have investigated specific aspects of language rather than everyday communication as a whole. The studies that have investigated the relationship between cognitive impairment and everyday communication have profiled cognitive impairment coarsely and used measures of

communication which did not focus on the ability and motivation of people with Parkinson's disease to perform Activities of Daily Living (Whitworth 1999, Miller 2008b).

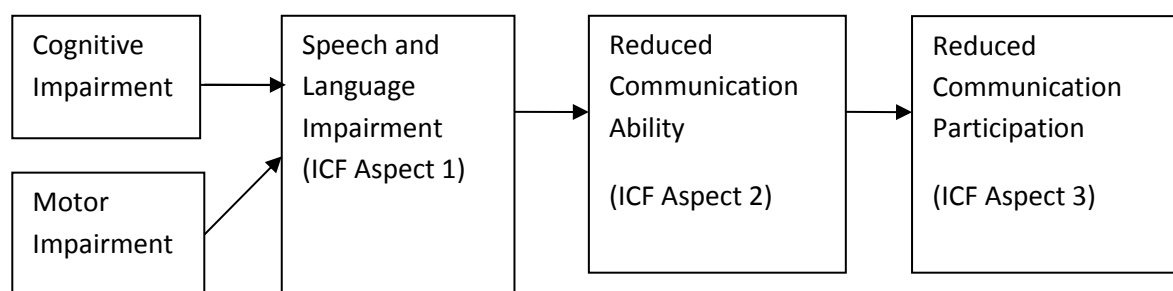
3.3 Speech acoustics and intelligibility

Studies have shown that people with Parkinson's disease are impaired in a range of aspects of speech production (Skodda 2008, Jiang 1999, Sapir 2010). However, the potential contribution of cognitive impairment to these speech impairments has not been established. No thorough investigation of the speech acoustics of British people with Parkinson's disease has been conducted. Existing American work often focuses on specific aspects of speech acoustics rather than providing an overview. It has not been established using thorough comparative methodology which aspects of speech acoustics are most important in determining how intelligible people with Parkinson's disease are. Moreover, there has been no thorough overview of the potential contributions of anxiety, depression, and demographic factors including age, gender, disease duration and medication taken to speech acoustics and intelligibility.

3.4 Study rationale

3.4.1 Research

Previous research on the impact of cognitive impairment in Parkinson's disease on speech, language and communication has focused strongly on the impairment of speech production and specific aspects of language rather than how it affects social communication. Studies that have measured communication have focused on impairments of specific aspects of social communication in Parkinson's disease such as perception of humour rather than how cognitive impairments affect communication in Activities of Daily Living. There is in particular a lack of work covering all four stages of communication impairment in Parkinson's disease. These are summarized by this diagram (ICF refers to the World Health Organization's International



Classification of Functioning (WHO 2001):-

This study is designed to fill this gap. Moreover, the vast majority of work conducted on the impact of Parkinson's disease on speech and communication has been conducted on American English and in the context of US culture and healthcare. This study intends to replicate and extend some of this work in a UK context. This study aims to increase knowledge about the effect of cognitive impairment on speech, language and communication in Parkinson's disease, with a greater focus on social communication than in previous research.

3.4.2 Outcomes from the research

There are three ways in which this study aims to bring clinical benefit to people with Parkinson's disease with Parkinson's disease.

3.4.2.1 Validation of a communication participation scale

One of the greatest concerns of people with Parkinson's disease with Parkinson's disease is how their speech and language impairments affect their ability and motivation to communicate in everyday life (Miller 2008b). Moreover, the ICF (WHO 2001) emphasizes the importance of communication abilities and communication participation. The Royal College of Speech and Language Therapists' Communicating Quality guidelines state that a goal of speech and language therapy (SLT) for progressive neurological disorders is to "maximize a client's communication potential within their environment and to enable maintenance of communication skills for the longest possible duration" (Van der Gaag 1996:81). The degree of focus placed by Speech and Language Therapists (SLTs) on everyday communication activities appears to be variable. In a national survey of 185 SLTs, Miller (2010a) found that only 12% used group therapy to address psychosocial aspects of communication in Parkinson's disease. Another 26% used discussion, counselling or therapy just involving the person with Parkinson's disease and their immediate family. Sixteen percent referred people with Parkinson's disease to other support services for communication related problems. In the UK there is no widely used objective means of assessing communication participation and no communication participation scale has been validated in the UK. We believe that once validated in the UK by our study, the Communication Participation Item Bank (Baylor 2009) could provide a very useful objective means of clinically measuring the impact of Parkinson's disease on the ability and motivation of people with Parkinson's disease to communicate in everyday life, and would help clinicians in their assessment and treatment of people with Parkinson's disease.

3.4.2.2 Greater understanding of factors affecting intelligibility and conveyance of emotion in Parkinson's disease

Our study will include a thorough assessment of which acoustic measures are most influential in determining how easily a person with Parkinson's disease can be understood and how whether being difficult to understand according to an SLT assessment will lead to people with Parkinson's disease being less able and motivated to communicate socially. There is a need for a UK-based study on this topic since the vast majority of previous research on speech acoustics in Parkinson's disease has used American English, which differs substantially from British English in its acoustic properties. This information could be useful for SLTs when deciding which aspects of speech to target most during therapy. Our study will also extend a small study by Miller (2008b) which showed that it was more difficult for listeners to identify the intended emotion of people with

Parkinson's disease when video data were available. This will provide greater understanding of the difficulties people with Parkinson's disease have in conveying emotion, and may help SLTs to assist their clients in this regard.

3.4.2.3 Potential for further investigation of how SLT could address the cognitive factors affecting communication in Parkinson's disease.

SLT for Parkinson's disease is based on SLT for dysarthric stroke patients (van der Gaag 1996). We know from the fields of Physiotherapy and Occupational Therapy, that techniques that work for stroke sometimes are very ineffective for Parkinson's disease. For example, people with walking difficulties post-stroke often find it useful to hold onto furniture. However, in PD this therapeutic technique would more likely increase episodes of freezing. There is considerable anecdotal evidence that people with Parkinson's disease enjoy and benefit from SLT. In a national survey of 168 people with Parkinson's disease (Miller 2010b), 86% of people with Parkinson's disease reported that they believed that SLT had exercised a positive effect on their communication and swallowing. However, concerns were raised about insufficient access to SLT. Forty-three percent of respondents had not had any contact with SLT services, and the biggest complaint from people with Parkinson's disease was that they did not have enough sessions with the SLT.

There is no conclusive scientific evidence as to whether current SLT for PD is effective or not (Deane 2001). SLT primarily addresses movement-disorder related speech impairments such as speech breath control, swallowing, rate of speech and loudness. The extent to which SLT addresses issues relating to everyday communication is variable (Miller 2010a). Moreover, SLT for PD doesn't address the cognitive factors behind the speech, language and communication impairments. Increased knowledge about these factors may be able to lead to the development of therapies which address the cognitive side of the speech, language, and communication impairments in PD.

4 AIMS

4.1 Primary aim

To assess the impact of cognitive impairment on speech, language and communication in Parkinson's disease.

4.2 Secondary aims

- To assess the relationship between cognitive impairments and communicative participation

- To assess the relationships between cognitive impairments and language, the acoustic quality and intelligibility of speech
- To characterize the acoustic qualities of both conversation partners' and people with Parkinson's disease' speech and investigate which acoustic properties contribute most to intelligibility.
- To assess the impact of anxiety, depression and demographic factors on cognition, speech acoustics, intelligibility and communicative participation
- To validate in the UK the Communicative Participation Item Bank including test-retest reliability and validity assessment using the Communicative Effectiveness Survey
- To create a database of audiovisual recordings of the speech of people with Parkinson's disease and their conversation partners for the benefit of future research and training of Speech and Language Therapists

5 STUDY DESIGN

5.1 Summary of study design

A cross-sectional case-controlled observational design will be used in order to assess the impact of cognitive impairments on speech, language, and communication in Parkinson's disease. 40 people with Parkinson's disease and their conversation partners will be recruited from the speech and language therapy Clinics at the Norwich Community Hospital (NCH) and the Neurology and Medicine for the Elderly Clinics at the Norfolk and Norwich University Hospital (NNUH). As the study is purely observational, no interventions will be carried out. The study will involve one appointment. At the beginning of the appointment, there will be time for the participants to discuss the study with the researcher before consent is sought. Once consent is obtained, the research procedures will take around 45 minutes. Due to travel being a major barrier in studies involving Parkinson's disease and the fact that our target population covers a fairly wide geographical area, we will offer a choice of venue for the study. People with Parkinson's disease and their conversation partners will either visit the Clinical Research & Trials Unit (CRTU) Norwich or be visited in their own home. One short questionnaire will be posted out 2 weeks after the study visit.

At the study visit, written informed consent will be obtained in writing. For people with Parkinson's disease, the signed consent form will be sent to the participants' General Practitioner (GP) with the participants' knowledge. The participants will be given a copy and the research team will keep a copy. Then, the person with Parkinson's disease and their conversation partner

will be enrolled into the study. Both participants will read out sentences from the Assessment of Intelligibility in Dysarthric Speech (AssIDS) and then have a conversation. They will also be asked to read four sentences with different emotional intonation patterns (happy, sad and neutral). Then the person with Parkinson's disease will complete the study questionnaires. The conversation partner may provide assistance with writing the questionnaires if required but may not choose answers for the person with Parkinson's disease. A person with Parkinson's disease who is unable to indicate their responses would have to be excluded. The questionnaires consist of a cognitive assessment, an assessment of anxiety and depression and two questionnaires about communication participation. Participants who travel to the CRTU Norwich will be reimbursed for their travel costs from the NHS Norfolk area.

Speech will be analyzed using Praat software (Boersma 2010). Characteristics, including loudness, of people with Parkinson's disease' and conversation partners' speech will be compared. Intelligibility will be assessed using a panel of listeners. Regression analysis will be used to determine which speech characteristics are most important for intelligibility. The relationships between cognition, speech intelligibility and communication participation will be assessed using regression and Analysis of Variance techniques.

5.2 Measures

- Montreal Cognitive Assessment (MoCA)
- Hospital Anxiety and Depression Scale (HADS)
- Communication Participation Item Bank
- Communication Effectiveness Survey (CES)

5.3 Study participants

The study is aimed at adult people with Parkinson's disease with idiopathic Parkinson's disease with problems with their communication. We will recruit people with Parkinson's disease from the Speech and language therapy Clinics at the NCH and the Neurology and Medicine for the Elderly clinics at the NNUH. Eligible people with Parkinson's disease will answer positively to the questions "Do you find that people have more difficulty understanding what you say than they used to?" or "Do you find that people ask you to repeat what you say more often than they used to?". These people with Parkinson's disease will be invited to give the conversation partner information pack to an adult who knows them, and who they feel comfortable speaking with. We will call this person the conversation partner.

5.3.1 Inclusion criteria for people with Parkinson's disease

- All adult people with Parkinson's disease (i.e. aged over 18) with a clinically made diagnosis of probable Idiopathic Parkinson's disease. This is taken to mean the person will meet three of the four UK Brain Bank diagnostic criteria for Parkinson's disease.
- Experiencing difficulties with their speech and/or communication, answering positively to to the questions "Do you find that people have more difficulty understanding what you say than they used to?" or "Do you find that people ask you to repeat what you say more often than they used to?"
- Are native English speaking and literate. This is essential for the speech analysis and would exclude less than 1% of the elderly population of Norfolk.

5.3.2 Exclusion criteria for people with Parkinson's disease

- Lack competence to consent by reason of dementia or any other reason
- Not a native English speaker (we estimate that this would exclude less than 1% of the elderly population of Norfolk)
- Unable to indicate questionnaire responses either directly or with the assistance of their conversation partner
- Parkinsonism due to another neurological condition or trauma (e.g. stroke)
- Have any condition in addition to PD that could negatively affect speech eg post-stroke dysarthria or oropharyngeal cancer

5.3.3 Inclusion criteria for Conversation partners

- An adult invited by the participant with Parkinson's disease, who knows the person with Parkinson's disease, and with whom they feel comfortable speaking with.
- Are native English speaking and literate. This is essential for the speech analysis and would exclude less than 1% of the elderly population of Norfolk.

5.3.4 Exclusion criteria for conversation partners

- Lack competence to consent by reason of dementia or any other reason
- If conversation partners have had conditions that would substantially affect the quality of their speech, they will be excluded from the analysis

5.3.5 Incentives

Participants who travel to the CRTU Norwich will be reimbursed for their travel expenses from the NHS Norfolk area. Study-related postage costs will also be covered.

5.4 Study procedures

5.4.1 Recruitment

The participant identification centres will be the Neurology and Medicine for the Elderly clinics at the Norfolk and Norwich University Hospital as well as the Speech and Language Therapy clinics at the Norwich Community Hospital. Members of the clinical care team will identify people with Parkinson's disease meeting the study inclusion criteria supplied by the researchers from their current caseload or database. These people with Parkinson's disease will be given a participant information pack (PIP) containing an information leaflet for people with Parkinson's disease, information leaflet for conversation partners, informed consent form for people with Parkinson's disease and informed consent form for conversation partners. People with Parkinson's disease will be invited to give the conversation partner pack to an adult they would be willing to have a conversation with. There will be a reply slip for potential participants to express interest in the study to the research team. Upon receipt of the reply slip, a member of the research team will telephone the potential participants to discuss the study and make an appointment for the study.

5.4.2 Informed consent for study

At the start of the study visit, the researcher will make an assessment of competency. It will be made clear that participants are free to withdraw from the study at any time for any reason without prejudice to future care, and with no obligation to give the reason for withdrawal. Participants will have had the chance to consider the PIP for at least a week before the study. Half an hour will be set aside to discuss the study and obtain consent at the start of the study visit. Written informed consent will be obtained from both person with Parkinson's disease and their conversation partner by means of a participant dated signature and dated signature of the principal investigator (Appendices 12.5 and 12.6). These signatures will be obtained on the latest approved version of the informed consent form before any study procedures are performed. A copy of the signed informed consent will be given to each participant and a copy will be retained by the study team at the University of East Anglia (UEA). For people with Parkinson's disease, the original signed form will be sent to the participants' GP. At each data collection point ongoing verbal consent will be sought and subjects reminded of their right to withdraw should they not

want to continue (process consent). Data collected to the point of withdrawal will be retained in the study data set. This is stated in the information sheets.

5.4.3 Informed consent for database

Participants will be invited to consider donating the audiovisual recordings of their speech to be stored in a secure controlled-access database such as the University College London's (UCL) Communication Audio Visual Archive (CAVA) for the future use of responsible screened researchers and lecturers. If they agree to for their recordings to be archived, they will be asked to give written consent for their data to be stored and used in the ways explained to them. Recordings will be identified by codes and names will never be used. However guidance from the Data Commissioner has stated that people's faces are "personal information", and obviously participants could potentially be identified from this information. However, because facial expressions are important in expressing meaning in communication, and because there is evidence that PD may impact on the relationship between facial expressions and clarity of communication (Miller 2008a), we need to keep the visual recording of the people's faces as well as the audio recordings. This will be made clear to all participants before they sign consent for inclusion of their audiovisual recordings to be stored and used in the database.

It is clearly important to ensure that any dataset is used in a responsible manner, and in ways that respect the issues of confidentiality and identity outlined above. To this end we will require future researchers and lecturers who wish to access the videos to sign an agreement to use the data responsibly and in accordance with the consent we have obtained from data owners. All participants will be made aware of these issues and how we propose to deal with them, and will have an opportunity to ask questions and clarify concerns before being asked to give written consent for archiving to take place. Participants who do not give consent for their data to be archived are still eligible to take part in the rest of the study.

5.4.4 Study measures

When informed consent has been obtained, the principal investigator will conduct the assessments in the order specified below. The PI will be trained in administering questionnaires in a standardized way. The majority of the outcomes will be self-completed by the people with Parkinson's disease.

5.4.4.1 Sentence reading

The person with Parkinson's disease and then the conversation partner will be asked to read 16 sentences taken from the Assessment of Intelligibility of Dysarthric Speech (AssIDS) (Yorkston 1981). Additionally, participants will be asked to say four other sentences in a happy, neutral and sad way (see section 6.8). An example list is provided in section 12.11. This is expected to take around ten minutes per participant. These sentences will be analyzed for acoustic measures and intelligibility (see sections 6.4 and 6.6 for details of analysis).

5.4.4.2 Conversational speech

The person with Parkinson's disease and their conversation partner will be asked to have as natural a conversation as possible for a few minutes. The aim of this is to assess the ability of the person with Parkinson's disease to communicate naturally rather than just reading sentence lists. A non-emotive topic will be chosen to avoid distress such as "What is a favourite place you have visited?"

5.4.4.3 Baseline demographics

The person with Parkinson's disease and their conversation partner will be asked some background demographic questions such as age, gender, educational background and how many years they have lived in Norfolk. The people with Parkinson's disease will also be asked how long they have had Parkinson's disease, what medication they are taking for Parkinson's disease and about any swallowing difficulties they are having. These data will be recorded on the Case Record Form (CRF) and used as factors in the analyses.

5.4.4.4 Cognitive assessment (Montreal Cognitive Assessment (MoCA) (Nasreddine 2003))

The Montreal Cognitive Assessment (MoCA) is a brief cognitive assessment which takes around 10 minutes to administer. It covers a range of aspects of cognition relevant to Parkinson's disease. It has been validated in the English language in PD (Gill 2008). It has been shown to be more sensitive to the mild and subtle cognitive impairments of early PD than the Mini Mental State Examination (Hoops 2009) which is widely used in hospitals as a dementia screen, but only identifies major cognitive impairment or dementia. It is freely available for clinical use without permission and for non-commercial research with permission. We have obtained this permission from Tina Brosseau, Projects & Development Manager, Center for Diagnosis & Research on Alzheimer's disease (CEDRA), Montreal, Canada.

5.4.4.5 Anxiety and depression (Hospital Anxiety and Depression Scale (HADS) (Zigmond 1983)

The HADS identifies anxiety disorders and depression and has been validated in Parkinson's disease (Leetjens 2001). It is a short 14 item questionnaire which should take less than ten minutes to complete. Anxiety and depression have been identified as factors that can affect speech acoustics (France 2002) so it is important that we take a measure of them in order to reduce bias in our speech analyses. Should the HADS identify depression this information will be fed back to the person with Parkinson's disease immediately along with one of two information sheets, that recommends they contact their GP (moderate/severe depression) or refers them to relevant self-help websites (mild depression) (Appendices 12.3.1 and 12.3.2). A letter will also be sent (with the knowledge of the person with Parkinson's disease) to their GP informing them that their patient has been identified as having depression and informing them of what recommendations the research team has made to the person with Parkinson's disease.

5.4.4.6 Communication participation scales

We will validate the Communication Participation Item Bank in an UK PD population. It is currently in its final stages of development in the USA by Baylor and colleagues. We will be using a 48-item version of the scale for this study. **Further scale development is ongoing and it is possible that a shorter version will be available by the time we finish, in which case we can score the results using both the 48-item and shortened scales. Our steering committee lay adviser with Parkinson's disease has completed the scale in five minutes, and stated that it will not take more than ten minutes to complete.** This scale is a self-report questionnaire assessing the ability and motivation of people with Parkinson's disease to communicate in a range of situations. Appendix 12.10.3 contains **the 48-item scale**. In order to validate a new scale, we have to give it twice to each participant. The first time will be during the study visit. Then it will be sent out by post two weeks after the speech recording session. This will allow us to assess the test-retest reliability of this scale. In order to test validity we will compare the Communication Participation Item Bank with the Communicative Effectiveness Survey (Appendix 12.10.4). It is an eight item questionnaire which has been developed and validated in the USA by Donovan (2008). It is the only other communicative participation scale which to our knowledge has been studied in Parkinson's disease.

5.4.5 Recording

Audiovisual recordings will be made of the sentence reading and the conversation using an SD card video camera. A table top microphone will be used to provide a back-up audio source so that recording sessions are not wasted in case of technical problems with the audio recording on

the video camera. People with Parkinson's disease will not be recorded while filling out questionnaires. The recordings will be analyzed for acoustic measurements and intelligibility.

5.4.6 Archiving

For those people with Parkinson's disease and conversation partners who provide separate consent for the archiving of the audiovisual recording of their speech, recordings will be archived on a controlled-access database such as the UCL CAVA. This will provide access to the recordings for suitable researchers and lecturers in future, preventing the need for the same data to be collected again. These data would be most useful for further research on this relatively new field of communication in Parkinson's disease and also for training of SLT students to become more familiar with the speech of a client group they may work with in future. The database and consent procedures for it are outlined in section 5.4.3.

5.4.7 Follow up

Two weeks after the study visit, another blank copy of the Communication Participation Item Bank will be sent by post. The reason for this will be explained on the information leaflets. This process is required in order to validate a new scale (see section 5.4.4.6)

6 ANALYSIS

Statistical analysis will be conducted using the statistics software SPSS. All tests listed presume that the assumptions for the use of parametric statistical tests are met. If this is not the case, appropriate transforms or non-parametric tests will be used.

6.1 Number of participants

A target sample size of 40 is sufficient to detect a correlation of 0.44 between the cognition and communication measures with 90% power according to a statistical power for correlation calculator (Arsham 1994). Having consulted participant identification centres, we believe that this sample size is achievable within the one year recruitment timescale afforded by a PhD. This allows for potential drop out of around 10% since we expect the cognition and communication measures to display a moderate correlation of around 0.5.

6.2 Speech acoustics

The speech of the same people with Parkinson's disease and conversation partners will be analyzed acoustically using phonetic software such as Praat (Boersma 2010). We have chosen measures that cover a range of the areas that have been suggested to be affected in motor

speech disorders. These broad areas are voicing control (function of the vocal cords), breath control, tongue control, and speech rhythm. These measures have never been used before in the context of Parkinson's disease in British English. Some of the measures have been studied in Parkinson's disease in the USA or other countries, whilst other measures we are using for the first time in Parkinson's disease. We would like to conduct a thorough investigation of how the speech of people with Parkinson's disease differs from their conversation partners, and which of these differences make their speech more difficult to understand. Here is a list of our acoustic analyses:-

6.2.1 Voicing control

- Fundamental frequency variance (This is related to how wide a pitch range we feel the speaker has)
- Voice onset time ratio (a measure of how long the vocal cords take to vibrate after releasing the closure in a /t/, /p/ or /k/ sound expressed as a percentage of total word duration)
- % jitter (a measure of variation in frequency of vibration between successive vocal cord cycles)
- % shimmer (a measure of variation in amplitude of vibration between successive vocal cord cycles)
- Cepstral peak prominence (an overall measure of voice quality)

6.2.2 Breath control

- Mean intensity (average loudness)
- % intensity decay (a measure of reduction in loudness over a section of speech)

6.2.3 Tongue control

- Formant Centralization Ratio (a measure of how different vowels are from each other)
- Variance of /s/ noise amplitude (a measure of how much the loudness of the hissing sound in an s varies over time)

6.2.4 Speech Rhythm

- Average speech rate
- Speech acceleration

- Pauses and speech repetitions
- Pairwise Variability Index (Low 2000) (a measure of the relative duration of successive vowels)

We will use suitable regression and/or Analysis of Variance techniques to analyze these data. We will investigate how the speech of people with Parkinson's disease and their conversation partners differed, and what were the effects of demographic factors, anxiety, depression and cognition.

6.3 Speech intelligibility

6.3.1 Assessors

We will ask students and staff at the University of East Anglia to act as collaborators to the research team by acting as assessors in the intelligibility analysis. Final year speech and language therapy students, anyone who is currently working with groups for people with Parkinson's disease and those who have a close relative with Parkinson's disease are not eligible to be assessors. Invitation of assessors will take place through posters, advertisements on the university website, lecturers and correspondence. Assessors will be offered the opportunity to enter into a prize draw for one £25 and five £5 Marks and Spencer vouchers. We will recruit 80 collaborators. Each assessor will be required for approximately one hour. All assessors will sign a confidentiality agreement to say that should they recognize any of the participants, they will not disclose this fact or the fact that they have Parkinson's disease to anyone. They will also be subject to University procedures on appropriate behaviour and be supervised by a member of the Study Management Group. In addition, the participation of assessors in the study will be kept confidential. Assessors will be asked to give their name, school of study and should they wish to enter the prize draw their UEA email address. However, all personal data will be stored in a locked filing cabinet in a locked room at the University and not used for analysis or presentation of results. The University of East Anglia would only find out about assessors' participation in the study should there be need to take disciplinary action against assessors for misbehaviour in the course of the research.

6.3.2 Methods

Assessment will be conducted in the University of East Anglia Allied Health Professions Communication Laboratory. Each assessor will listen to sentences taken from the speech of a range of people with Parkinson's disease and conversation partners. Sentences will be presented using suitable software such as Superlab (Aboud 1997). In the first part of the session, assessors'

task will be to enter the sentences they hear and to rate how confident they are of their decision. In the second part, the assessors' task will be to tick a box to say whether they believe the speaker intended to sound happy, sad or neutral. Allocation of sentences to assessors will be Latin Square counterbalanced. This means that each listener will listen to a subset of the recordings. Presentation order will be randomized.

6.3.3 Analysis

Factors affecting intelligibility and mood identification will be investigated using suitable regression models and Analyses of Variance. The scoring measures will be % words correctly identified and % moods correctly judged respectively. These factors will include whether the speaker had Parkinson's disease or not, demographic factors, acoustic measures, cognition, anxiety and depression. The effect of audiovisual versus audio only listening will also be investigated in the mood identification part.

6.4 Communicative Participation

Cohen's Kappa coefficient will be used to assess the reliability of scores on the two administrations of the Communicative Participation Item Bank and the relationship between scores on the Communicative Participation Item Bank and the Communicative Effectiveness Survey. Suitable regression and Analysis of Variance techniques will be used to assess factors affecting communication participation: including cognition, depression, anxiety, medication, disease presence and duration, speech acoustics, speech intelligibility and demographic factors.

7 PROJECT TIMETABLE

The project will take place over 2 years (24 months) including time for analysis, writing up and disseminating results. This follows a year of preparation which started in October 2010. The scheduled start date for recruitment is **January 2012**. It is expected to take around one year. Analysis and dissemination will be the focus of months 12-24. Dissemination will include a lay summary to study participants, appropriate correspondence to stakeholders summarising the study's results, presentations at conferences and publication in relevant peer reviewed journals.

Maxwell Barnish will chair the Study Management Group (SMG) which is expected to meet quarterly. This will consist of MB, KD, SH and ZB. This will monitor the progress of the study. In months in which the SMG does not meet, MB will meet with at least one of the supervisors.

Katherine Deane will chair the Steering Committee (SC) which is expected to meet quarterly. In addition to all members of the SMG, medical statistician Dr Allan Clark of the Norwich Medical

School, University of East Anglia, two lay members with Parkinson's disease, representatives from the Norwich Community Health and Care Trust speech and language therapy team and representatives from Medicine for the Elderly and Neurology at the NNUH will be invited to join the SC. This committee will oversee recruitment rates, any AEs and technical problems encountered in the study.

8 QUALITY ASSURANCE PROCEDURES

The study will be conducted in accordance with the current approved protocol, International Conference of Harmonisation (ICH) guidelines for Good Clinical Practice (GCP), relevant regulations and standard operating procedures. Regular monitoring will be performed according to ICH-GCP.

8.1 Scientific review

The study proposal was reviewed by the Health and Social Sciences Research Institute of the University of East Anglia prior to the award of a University of East Anglia PhD Studentship to Maxwell Barnish. The full protocol has been reviewed by the academic supervisors and circulated to the Steering Committee.

8.2 Statistical review

The statistical elements of the protocol were reviewed by medical statistician Dr Allan Clark of the Norwich Medical School, University of East Anglia.

8.3 Roles and responsibilities

Maxwell Barnish will have overall responsibility for the study. He will chair the Study Management Group (SMG) which is expected to meet quarterly for the duration of the study. He will lead in the analysis and writing up of the results and their dissemination. He is also an experienced phonetician and will conduct the acoustic analysis.

Katherine Deane will act as primary academic supervisor and oversee the running of the study. She will chair the Steering Committee (SC) which is expected to meet quarterly for the duration of the study.

Simon Horton and Zoe Butterfint will act as secondary academic supervisors and oversee the running of the study. ZB is an experienced phonetician and will also oversee the acoustic analysis and advise Maxwell Barnish on this matter.

Medical statistician Dr Allan Clark of the Norwich Medical School, University of East Anglia will advise on data analysis.

8.4 Involvement of people with Parkinson's disease

The information leaflet, invitation letter and consent form for people with Parkinson's disease have been reviewed by lay people including people with Parkinson's disease prior to their submission. This is in order to ensure they are suitably worded and that the study is acceptable to the target population. People with Parkinson's disease are on the Steering Committee which oversees study design, progress and analysis. At the conclusion of the study, a lay summary of our findings will be sent to all participants and to Parkinson's UK.

8.5 Study Management Group

The study will be coordinated by a Study Management Group (SMG), comprising the Principal Investigator MB, Primary Academic Supervisor KD and Secondary Supervisors SH and ZB. It will meet quarterly and be chaired by Maxwell Barnish. It will monitor progress of the study and also act as a supervisory team meeting.

8.6 Steering Committee

A Steering Committee will be established to oversee the conduct and progress of the study and will meet quarterly. It will be chaired by Katherine Deane. In addition to all members of the SMG, medical statistician Dr Allan Clark of the Norwich Medical School, University of East Anglia, local people with Parkinson's disease, representatives from the Norwich Community Health and Care Trust speech and language therapy team and representatives from Medicine for the Elderly and Neurology at the NNUH will be invited to join the SC. This committee will oversee recruitment rates, any AEs and technical problems encountered in the study.

8.7 Managing risk

The researchers will make every effort to ensure that risks are minimised and study participants will be provided with appropriate contact details in case of emergency. Any complaints will be handled by current National Health Service procedures.

People with Parkinson's disease identified as having depression will be given information sheets with recommendations for management in line with current NICE guidance (NICE 2009). In addition their GPs will be informed if we detect that participants may have depression.

We will comply with the principles of GCP, local Trust and University of East Anglia guidelines including the Lone Worker Protocol and Standard Operating Procedures for the management of any adverse events.

Adverse events will be entered on Case Record Forms (CRF).

Serious adverse events will be reported to the sponsor and research ethics committee within 15 days of the PI being aware of the event as specified by GCP. Following UEA policy, these will also be reported to the UEA Research Enterprise and Engagement Office. Safety reports will be submitted to regulatory bodies whenever required by current regulations.

9 ETHICS

9.1 Declaration of Helsinki

The Principal Investigator will ensure that this study is conducted in full conformity with the current revision of the Declaration of Helsinki (last amended October 2000, with additional footnotes added 2002 and 2004).

9.2 ICH Guidelines for Good Clinical Practice

The Principal Investigator will ensure that this study is conducted in full conformity with relevant regulations and with the ICH Guidelines for Good Clinical Practice (CPMP/ICH/135/95) July 1996.

9.3 Approvals

This protocol, the Informed Consent Form, Information Leaflets and other study documents will be submitted to the Norfolk NHS Research Ethics Committee for approval. NHS Research and Development permission will be sought from the Norfolk Community Health and Care NHS Trust for the use of the NCH as a Participant Identification Centre, and from the NNUH Foundation Trust for the use of the University of East Anglia Clinical Research and Trials Unit as a research site and the Neurology and Medicine for the Elderly clinics as Participant Identification Centres. Governance approval for home visits will be sought from the University of East Anglia which will act as the research site for these visits. The PI will submit and, where necessary, obtain approval from the above parties for any substantial amendments to the original approved documents.

9.4 Participant confidentiality

All data will be handled in accordance with the Data Protection Act 1998 which requires data to be anonymised as soon as it is practical to do so. Personal data including encrypted external hard drives containing video files will be stored in a locked filing cabinet in a locked room at UEA. CRFs and copies of consent forms and demographic information will be stored in the Study Master File (SMF) which will be kept in this locked cabinet. Only the principal investigator (MB) and the academic supervisors (KD, SH and ZB) will have access to these documents. KD and SH have extensive experience of clinical research and they as well as MB are trained in Good Clinical Practice. The PI will ensure that the participants' anonymity is maintained.

Anonymised study results and audio recordings will be stored on the UEA computer network. Access to this network is controlled by a password. The participants will be identified only by a participant ID number on CRFs and any electronic database. The documents linking these codes

with names and addresses will be stored securely in the SMF and only accessible by the principal investigator and the academic supervisors.

Guidance from the Data Commissioner has stated that people's faces are "personal information", and obviously participants could potentially be identified from this information. However, because facial expressions are important in expressing meaning in communication, and because there is evidence that PD may impact on the relationship between facial expressions and clarity of communication (Miller 2008a), we need to keep the visual recording of the people's faces as well as the audio recordings. This will be made clear to all participants before they sign consent to take part in the study or for inclusion of their audiovisual recordings to be stored and used in the database. By consenting to take part in the study, participants are agreeing for these recordings to be used for the listener study and then destroyed at the end of the study. This will be made clear to participants on the PIL and before consent is sought.

Video files will be stored on encrypted external hard drives which will be stored in a locked filing cabinet in a locked room at the UEA. Recordings will be made using an SD card video camera. As soon as possible after the study visit, recordings will be transferred to an external hard drive and deleted from the camera. External hard drives will be stored in a locked filing cabinet in a locked room at the UEA. If the participants choose to come to CRTU, at the end of the session, the researcher will transfer all video files from the camera to the encrypted external hard drives and delete the videos from the camera. If the participants choose to be visited at home by the researcher, at the end of the session, the researcher will transfer the video recordings from the camera to an encrypted sector on the study laptop for transit back to the university and delete them from the camera. The laptop will be locked in the boot of the researcher's car and will not be taken into the study venue. Upon arrival back at the university, the researcher will transfer the video files from the encrypted sector of the laptop hard drive to an encrypted external hard drive, which will be stored in a locked filing cabinet in a locked room at the University of East Anglia. The researcher will delete the video files from the laptop.

9.5 Identification of depression

All data will be collected by research team members who will hold an honorary NHS contract and will adhere to trust and university policies. Should the HADS identify depression this information will be fed back to the person with Parkinson's disease immediately along with one of two information sheets, that recommends they contact their GP (moderate/severe depression) or refers them to relevant self-help websites (mild depression) (Appendix 12.3.1 & 12.3.2). A letter will also be sent (with the knowledge of the person with Parkinson's disease) to their GP informing them that their patient has been identified as potentially having depression and informing them of what recommendations the research team has made to the person with Parkinson's disease (Appendix 12.3.3).

10 DATA HANDLING AND RECORD KEEPING

All Investigators involved with this study will comply with the requirements of the Data Protection Act 1998 with regard to the collection, storage, processing and disclosure of personal information and will uphold the Act's core principles. The participants will be identified by a study specific participant number and/or code in any database. The name will not be included in any study data electronic file. All anonymous electronic study data will be entered onto secure

computer systems at the University of East Anglia. Computers used to collate data will have limited access measures via user names and passwords. Hard copy study data will be stored in a locked filing cabinet in a locked room at the UEA. Signed informed consent forms will be stored in the Study Master File in a locked filing cabinet at the University of East Anglia. Video files will be stored on encrypted external hard drives in a locked filing cabinet at the University of East Anglia.

Study CRFs will be completed by the principal investigator and stored securely at the UEA in the SMF. At the end of the study, participants will receive a lay summary of the study results. Study data forms and the study database will be archived. Anonymised study associated documents will be stored on the UEA computer network for five years from study completion. Personal information will be destroyed at the end of the study. The only exception to this will be videos for those participants who have given consent for their recordings to be archived on the secure controlled-access database.

10.1 Access to source documents / data

Source documents are original documents, data, and records from which participants' CRF data are obtained. CRF entries will be considered source data where the CRF is the site of the original recording (e.g., there is no other written or electronic record of data). All documents will be stored safely in confidential conditions. On all study-specific documents, other than the signed consent, the participant will be referred to by participant number/code alone. Direct access will be granted to the investigators as well as authorized representatives from the sponsor, host institution and the regulatory authorities to permit study-related monitoring, audits and inspections.

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Appendix 28: Protocol breach initial report

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Cambridge Central REC
Chair: Dr Rowan Burnstein

Norfolk REC
Chair: Dr Michael Sheldon

Victoria House
Capital Park
Fulborn
Cambridge, CB21 5XB

10th February 2012

Dear Dr Burnstein and Dr Sheldon,

Breach of protocol on two projects: Initial Report

11/EE/0179: The use of carer assisted adherence therapy for people with Parkinson's disease and their carers: a randomised controlled trial. CI: David Daley

11/EE/0274: An investigation of the relationships between speech and communication characteristics and cognitive status in people with Parkinson's disease. CI: Maxwell Barnish

We are writing to inform you of an error that has occurred in the handling of patient identifiable data, and the steps we are taking to rectify this.

David Daley's PhD project recruits people with Parkinson's disease who have problems adhering to their medication regimen. Maxwell Barnish's PhD project has almost identical eligibility criteria except that he is looking to recruit people with Parkinson's disease who have some degree of difficulty speaking and who may or may not be adherent.

I asked David Daley to identify patients suitable for Maxwell Barnish's PhD project from our study data. These are the patients who replied the study invitation, indicated their

interest in the study and returned the screening questionnaire but were adherent to their medication and thus not suitable for David Daley's project. Retrospective identifying of potential participants was allowed within Maxwell Barnish's study protocol where it was intended that clinic staff would identify potentially eligible patients (both retrospectively and prospectively) and send them an invitation pack by post from the clinic.

The error occurred when names and addresses of potentially eligible patients were transferred from David Daley (study team) from UEA, direct to Maxwell Barnish (UEA). This breaches David Daley's protocol.

Maxwell Barnish received the names and addresses of 90 patients (with the implicit information that they had Parkinson's disease). He then sent invitation packs to 44 of the patients inviting them to participate in his research. This breaches Maxwell Barnish's protocol.

Maxwell Barnish and David Daley consulted with me (their supervisor) whether this process was allowable and erroneously I agreed it was. We realised our error within a few days of the letters being sent.

We have currently suspended recruitment on both projects. Maxwell Barnish has destroyed the patient list as advised by the UEA Data Protection Officer. We have identified where in the process the error occurred (the letters should have been sent from clinic and not UEA). This will not be allowed to be repeated.

We are taking advice from the Data Protection Officers of NNUH and UEA regarding whether the Information Commissioner's Office needs to be informed. Also they will advise us regarding what we tell the patients involved. The Caldicott Guardian has also been informed via NNUH R&D and will work with us and the clinics to advise us if any further changes are required to our patient identification protocols. We have informed the R&D departments (NNUH and UEA) and the sponsor (UEA).

Maxwell Barnish, David Daley and I will repeat GCP and Data Protection Act training at the soonest possible opportunity.

We apologise for this error of judgement. We will keep in contact with you to inform you of our actions and would appreciate your advice on the ethical aspects of this breach.

Regards

Dr Katherine Deane

On behalf of the PGR supervisory teams.

cc: NNUH R&D, UEA REN, Sponsor UEA, Data Protection Officer UEA, Vice Chancellors Office UEA, Directors of PGR for FMH, NSC and MED at UEA

Appendix 29: Protocol breach progress report

Dr Katherine Deane BSc PhD
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 Edith Cavell Building
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 Norwich, NR4 7TJ
 Tel: 01603 59 7047
 Email: k.deane@uea.ac.uk

Cambridge Central REC
 Coordinator: Nicky Storey

Norfolk REC
 Coordinator: Anna Bradnam

Victoria House
 Capital Park
 Fulborn
 Cambridge, CB21 5XB

26th March 2012

Dear Ms Bradnam and Ms Storey,

Breach of protocol on two projects: Progress Report

11/EE/0179: The use of carer assisted adherence therapy for people with Parkinson's disease and their carers: a randomised controlled trial. CI: David Daley

11/EE/0274: An investigation of the relationships between speech and communication characteristics and cognitive status in people with Parkinson's disease. CI: Maxwell Barnish

Further to our initial report of the protocol breach the following actions have occurred.

1. The Research Governance offices of both UEA and NNUH (having taken advice from the Data Protection Officers for UEA and NNUH) wrote a joint letter to all 90 patients whose data had been inappropriately shared. (The letter is attached).
2. The NNUH Research Governance Committee met and recommended that Dr Deane, Dr Myint, Mr Daley and Mr Barnish complete training in ICH GCP and NHS Information Governance. The NNUH Research Governance Committee stated that they would be happy for recruitment to restart once certificates had been received from Dr Deane, Dr Myint, Mr Daley and Mr Barnish. This training is now in process.
3. David Daley submitted an amendment to ethics for consideration of variations to his project's recruitment process. (Protocol Version 2.0 dated 16.03.12).

We hope that you find that all of these actions have been appropriate and we await your ethical opinion on any further actions that we should undertake.

Many thanks for your time and attention to this matter,

Regards

Dr Katherine Deane

Appendix 30: UEA and NNUH joint letter regarding protocol breach

Dear

You may recently have received a letter inviting you to take part in a research study. The study is called: Factors affecting the speech of people with Parkinson's disease. This research is being conducted by a post-graduate student at the University of East Anglia (UEA) working in collaboration with Norfolk & Norwich University Hospital (NNUH).

Your name and address was mistakenly given to the student leading the above research by another post-graduate student who also is conducting research at NNUH within the same department. Your name and address was given to the post-graduate student leading the above stated study because the eligibility criteria for both research projects are very similar. This means the student researchers were looking for the same sort of people to take part in their respective studies. The two post-graduate students leading the research studies were unintentionally led to believe that this transfer of patient data (names and addresses) was legitimate. After this transfer of data both research teams realised this act was contrary to the approved protocols. This may have resulted in you being invited to take part in the above stated study.

Both studies have been reviewed by a NHS Research Ethics Committee and have received a favourable opinion. This means an independent expert panel have reviewed both research studies before allowing such research to be initiated at NNUH. However, this way of passing patient data between researchers was not part of the approval because it does not meet the requirements of the NHS Confidentiality Code of Practice or the Data Protection Act.

We want to reassure you that your personal information was not passed to anyone else, and the second student has now destroyed the list. Despite this being an honest mistake, both the students and their supervisors will receive additional training on NHS Information Governance, and we will make sure that in the future researchers have received this training.

We hope that this will not discourage you from taking part in research in future.

If you would like to talk to someone about this event, or need more information, please contact us:

Sue Steel 01603 591486

Kath Andrews 01603 286611

Yours sincerely

Sue Steel

Contracts Manager.

University of East Anglia

Kath Andrews

R&D Manager

Norfolk & Norwich University

Hospital NHS FoundationTrust

Appendix 31: Ethics approval for resumption of recruitment



Health Research Authority

NRES Committee East of England - Norfolk

Victoria House
Capital Park
Fulbourn
Cambridge
CB21 5XB

Sent by email 9 May 2012

Tel: 01223 598906

09 May 2012

Mr Maxwell S Barnish
m.barnish@uea.ac.uk
PhD Student
University of East Anglia
Room 0.27, Queen's Building
University of East Anglia
Norwich
NR4 7TJ

Dear Mr Barnish

Study title: An investigation of the relationships between speech and communication characteristics and cognitive status in people with Parkinson's disease.
REC reference: 11/EE/0274
Amendment number: Amendment #3 (Restart Amendment)
Amendment date: 24 April 2012
Amendment Details:

Formal request to re-start recruitment to study following protocol breach. Following the notification to Norfolk REC of a protocol breach, and the subsequent completion of necessary measures to ensure the breach was dealt with appropriately and does not occur again, we are now requesting a re-start of recruitment to the study. Actions Taken to Rectify: 1. Recruitment to both Maxwell Barnish's and David Daley's studies was stopped on 10.02.12; i.e. as soon as the protocol breach was identified. 2. All relevant parties were informed of the protocol breach and advised the research teams on their actions. Persons informed include the Research Governance offices of both Norfolk and Norwich University Hospital (NNUH) and University of East Anglia (UEA), the Data Protection Officers of NNUH and UEA, the projects' sponsor (Sue Steel, UEA), the Caldicott Guardian (NNUH), the Vice Chancellor's Office (UEA), the Directors of Postgraduate Students (UEA), School Directors of Research (UEA), and the Heads of Schools (UEA). 3. The Research Governance offices of both UEA and NNUH (having taken advice from the Data Protection Officers for UEA and NNUH) wrote a joint letter to all 90 patients whose data had been inappropriately shared. This has subsequently been posted out and queries from those contacted have been dealt with by the sponsor. 4. The NNUH Research Governance Committee met and recommended that Dr Deane, Mr Daley, Mr Barnish and Dr Myint (David Daley's primary supervisor) complete further training in ICH GCP and NHS Information Governance. The NNUH Research Governance Committee stated that they would be happy for recruitment to restart once certificates had been received from Dr Deane, Dr Myint, Mr Daley and Mr Barnish. This training has now been completed by all individuals and NNUH R&D has advised the study sponsor (Sue Steel, Contracts Manager UEA) that they are happy for the study to recommence.

The above amendment was reviewed by the Sub-Committee in correspondence.

Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Covering Letter	Email from M Barnish	24 April 2012
Notice of Substantial Amendment (non-CTIMPs)	Amendment #3 (Restart Amendment)	24 April 2012

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

R&D approval

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

11/EE/0274:

Please quote this number on all correspondence

Yours sincerely

Har Hari Kaur

PP-

Michael Sheldon MA, PhD
Chair

E-mail: har.hari.kaur@eoe.nhs.uk

Enclosures:

List of names and professions of members who took part in the review

NRES Committee East of England - Norfolk

Attendance at Sub-Committee of the REC meeting on 07 May 2012

<i>Name</i>	<i>Profession</i>	<i>Capacity</i>
Michael Sheldon MA, PhD	Retired Clinical Psychologist	Lay
Dr Robert Stone	General Practitioner	Expert

Also in attendance:

<i>Name</i>	<i>Position (or reason for attending)</i>
Miss Har Hari Kaur	Acting Assistant Co-ordinator

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

R&D approval

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

115/12014 Please quote this number on all correspondence


Yours sincerely


Michael Sheldon MA, PhD
Chair

E-mail: har.hari.kaur@nec.nhs.uk

Enclosures: List of names and professions of members who took part in the review

Appendix 32: Research and development approval for resumption of recruitment

 **Our Vision**
To provide every patient
with the care we want
for those we love the most

Norfolk and Norwich University Hospitals 
NHS Foundation Trust

Research & Development Office
Level 3 East
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Mr Maxwell Scott Barnish
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United Kingdom

direct dial: 01603 287806
direct fax: 01603 289800
e-mail: rdoffice@nnuh.nhs.uk
website: www.nnuh.nhs.uk

14 May 2012

Dear Mr Barnish

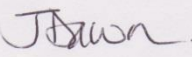
Re: R&D Reference Number: 2011NEUR05S (80-06-11)
Project Title: An investigation of the relationships between speech and communication characteristics and cognitive status in people with Parkinson's disease.

Thank you for your recent correspondence regarding amendment 3 for the above study. It was noted that the amendment has already received a favourable opinion from the Norfolk Research Ethics Committee.

Following review of the documentation I am pleased to inform you that there is no objection to this amendment.

If you have any queries regarding this or any other project please contact Seema Gopinath, Research Facilitator, at the above address. Please note, the reference number for this study is **2011NEUR05S (80-06-11)** and this should be quoted on all correspondence.

Yours sincerely


P2. **Kath Andrews**
Research & Development Manager

Carbon Copy: Dr Paul Worth, Sue Steel (sue.steel@uea.ac.uk)

Norfolk & Norwich University Hospitals NHS Foundation Trust

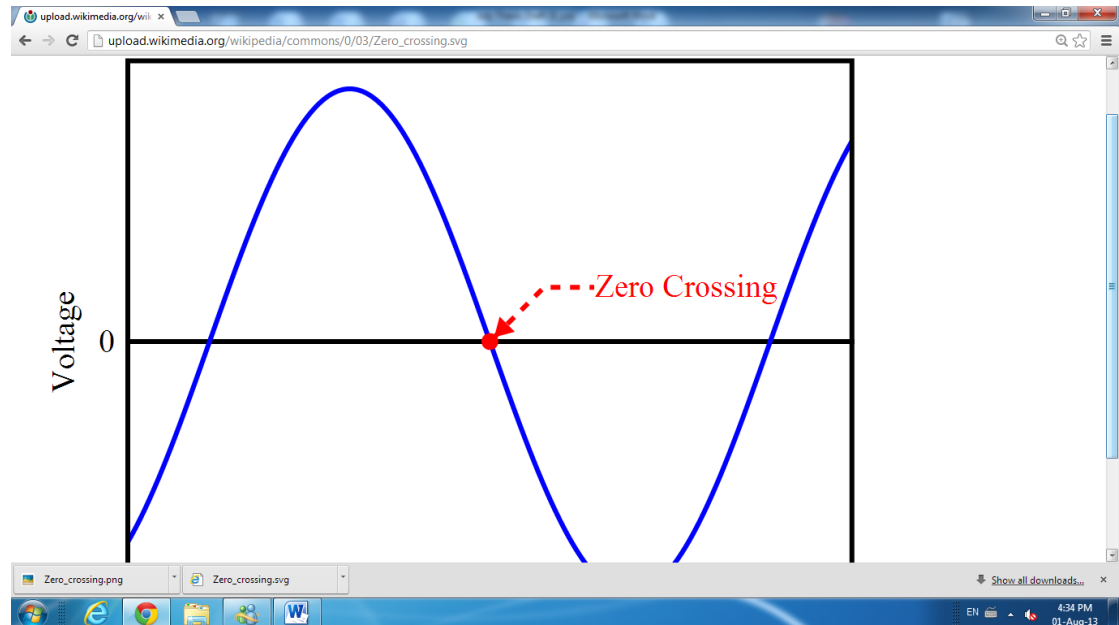
Appendix 33: More detailed phonetic segmentation criteria

I optimised the Praat configuration to suit my analyses. Prior to performing this optimisation process, I consulted the Praat manual ("Praat manual,") I selected cross-correlation rather than auto-correlation for F_0 trace calculation. The use of cross-correlation, which optimises for voice analysis, may be more appropriate for speakers who may have weaker voicing. I reduced the F_0 lower bound to 50 Hz from the default 75 Hz, due to the potential for a higher prevalence of creaky voice in PwPD. I retained the default voicing threshold at 0.45. Voicing threshold refers to how much evidence of periodicity must be present in the speech signal for the software to recognise the speech as voiced. The Praat manual acknowledges that sometimes the software can sometimes 'hallucinate' voicing at inappropriate places in the signal when cross-correlation is used. Therefore, prior to running analysis on a sentence, I screened it, using auditory, spectrographic and spectral information, to identify voicing errors. When an error was identified, I raised the voicing threshold in increments of 0.05 to a maximum of 0.6. If the error had not been eliminated by a voicing threshold of 0.6, or this process had caused significant negative consequences, I had to excise the problematic section of the F_0 trace for relevant analyses.

Now, I shall discuss how I made decisions regarding speech sound boundaries. Unlike in writing, there are usually no distinct boundaries between spoken sounds. Therefore, segmentation involves imposing arbitrary linguistic constructs onto what is essentially an acoustic continuum. However, segmentation was essential for performing these analyses. Therefore, I imposed segmentation criteria, but ensured that these were applied as consistently as possible.

In a simple context, a vowel was defined as lasting from the first downward zero-crossing after the start of periodic voicing until the first upward zero-crossing following the cessation of periodic voicing. The following image demonstrates the concept of a zero-crossing. The image uses an electrical current as an example; however the concept is equally applicable to speech waves. The term 'zero' in zero-crossing refers to the x-axis halfway up the diagram, above which the amplitude is deemed positive and below which it is deemed negative. A zero-crossing, therefore, occurs when the waveform, which is depicted in blue on the diagram, crosses this axis. The label 'zero-crossing' on the diagram shows a downward zero-crossing, that is to say when the waveform crosses the axis heading in a downward direction. An upward zero-crossing occurs when the waveform crosses the axis heading in an upward direction.

Figure 6: Illustration of a zero-crossing



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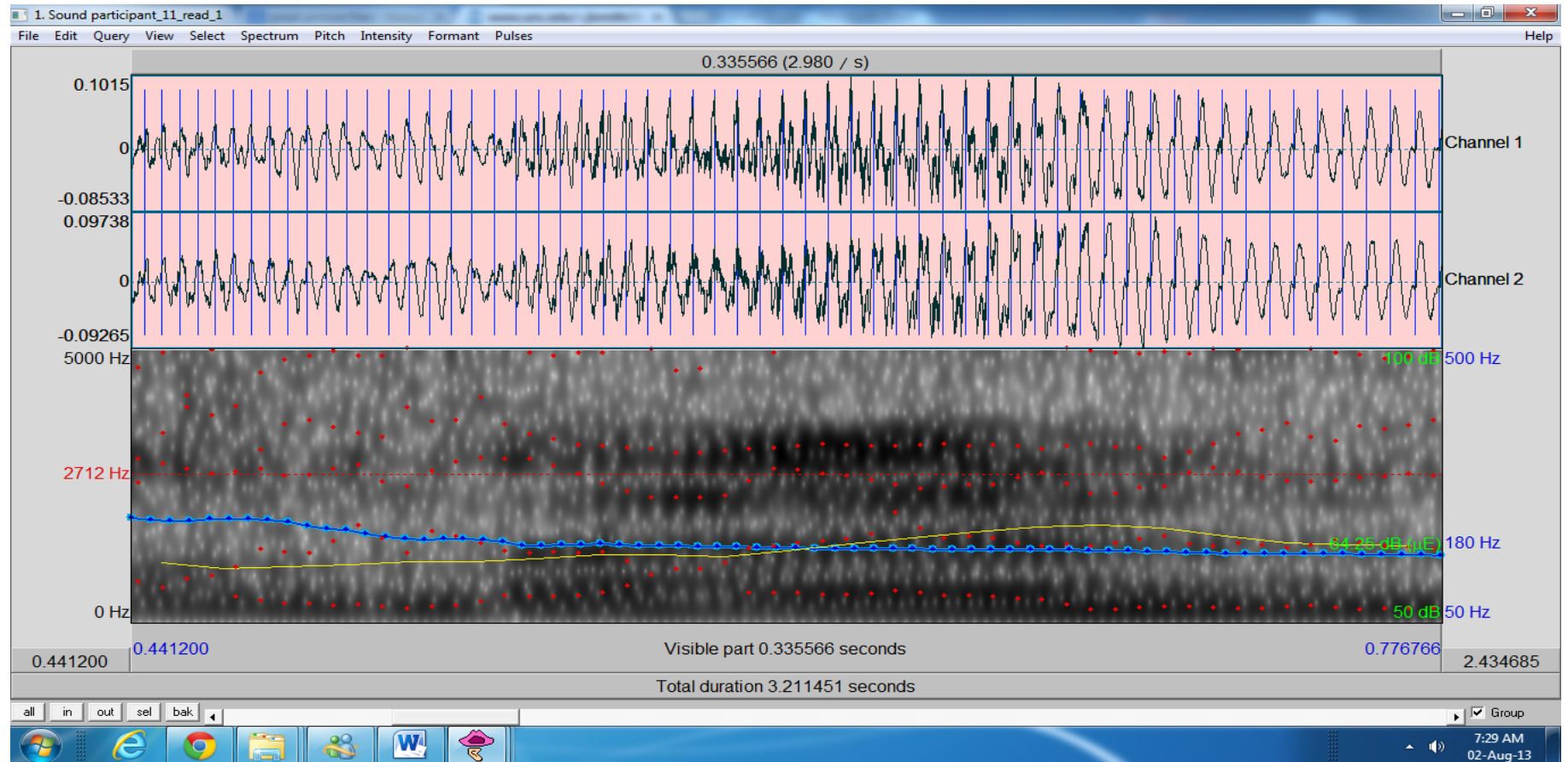
When defining vowels, it was important to remember that I was defining the specific vowel of interest, rather than the total period of voicing. For example, in some phonetic contexts, there could be other voiced sounds bordering this vowel. In this situation, I used a combination of auditory, spectral and spectrographic cues to delineate the vowel boundaries.

The waveform and spectrogram below (Participant 11, sentence one- 'moon') show a nasal-vowel-nasal sequence. In a nasal, such as /n/ or /m/, the oral cavity is closed and sound is radiated through the nasal cavity (Fujimura, 1962). This side branch can give rise to antiformants (Kent and Read, 2002), which reduce the amplitude of resonances. Some resonances are cancelled out, leading to spectral gaps.

In the centre of the spectrogram, there is a darker black section. This indicates greater intensity. This darker section corresponds to the vowel /u/. Either side of this vowel, there are lighter sections. These correspond to the less intense nasals /m/ and /n/. The nasal-vowel and vowel-nasal boundaries are indicated on the spectrogram by relatively abrupt changes in the spectrogram darkness, and shifts in the formant pattern, as indicated by the red dotted line.

For the sake of clarify, I have chosen to include an example with a well-defined boundary between the nasal and the vowel. However, some PwPD do not maintain sufficient control of the velo-pharyngeal port (Hoodin and Gilbert, 1989). The velo-pharyngeal port separates the oral cavity, which stretches from the vocal folds to the lips, from the nasal cavity. This can result in less clearly defined boundaries between nasal and non-nasal segments. In such cases, I relied on a combination of auditory, spectrographic and spectral cues to make my boundary decision.

Figure 7: Waveform and spectrogram showing segmentation of a nasal-vowel-nasal sequence



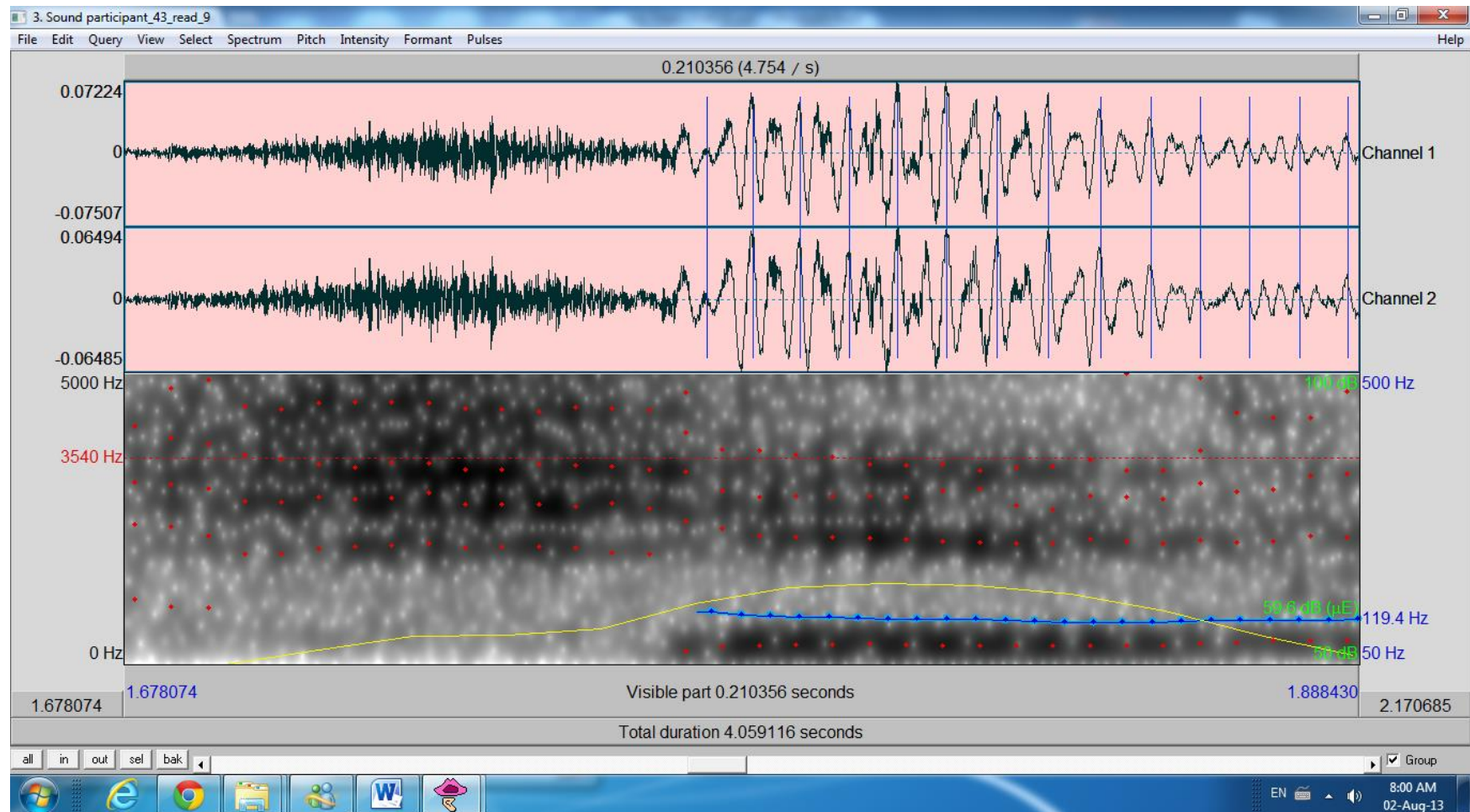
© Praat is freeware distributed under a GNU GPL licence. This notice also covers figures 8 and 9.

The waveform and spectrogram below (Participant 43, sentence nine- 'she') show a fricative-vowel sequence. Fricatives are produced with aperiodic turbulent energy, resulting from a narrow constriction in the vocal tract (Kent and Read, 2002).

On the right of the waveform, there is a periodic pattern corresponding to the vowel /i/. On the spectrogram, this can be seen in the dark formant horizontal bands (emphasised by the red dotted lines). The left side of the waveform and spectrogram contrasts markedly with the right side. It represents the fricative /ʃ/, as in the first sound of 'she'. The turbulence corresponding to the fricative is represented by the jagged line on the waveform and the high frequency band of aperiodic energy on the spectrogram. I marked the start of the vowel at the first downward zero-crossing (see above) after the start of periodicity.

For the sake of clarity, this spectrogram shows a relatively straightforward case. However, in the speech of some PwPD, the delineation is less clear. In this case, I applied a principle of predominance.

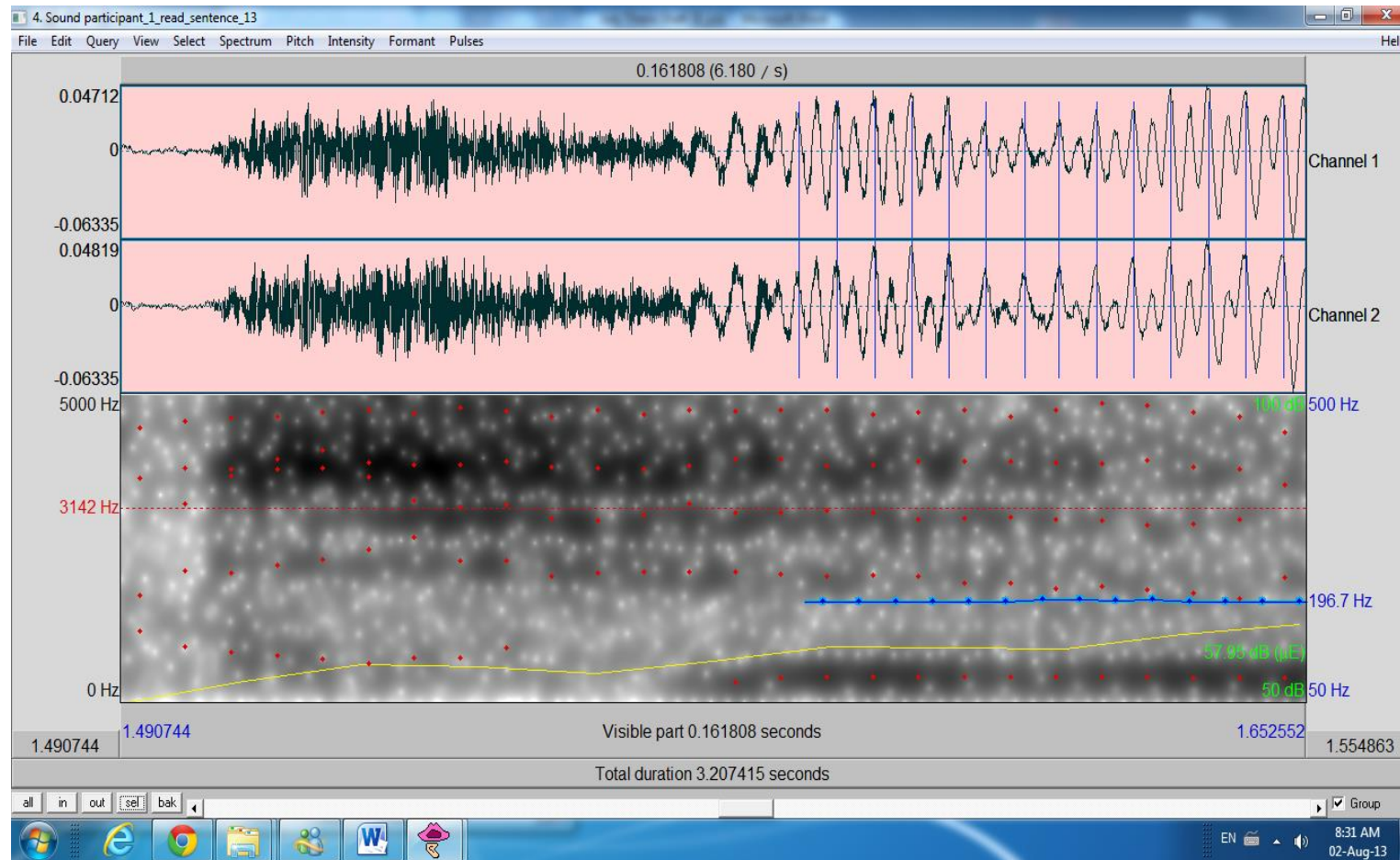
Figure 8: Waveform and spectrogram showing segmentation of a fricative-vowel sequence



The waveform and spectrogram below (Participant one, sentence 13- 'two') show a stop-vowel sequence. Stops, such as /t/, are produced by the release of pressure built up behind an obstruction in the oral cavity. They are defined in terms of dynamic (closing, closure, release) rather than static events (Johnson, 2012).

On the left of the waveform and spectrogram, there is a period of very limited activity corresponding to the closure. When the closure is released, there is a sudden release of built-up energy that is called a 'burst' or 'transient'. On the waveform, this is indicated by a sharp deviation from zero. On the spectrogram, this is shown by a dark vertical band of energy. Then, approximately half way through the sound file in the example, the stop yields to the following vowel. On the waveform, this is marked by the start of periodic waves. On the spectrogram, this is indicated by the end of the band of high-frequency aperiodic energy and the start of vowel formant bands. Additionally, 'striations' can be seen. These are vertical lines corresponding to vocal pulses. I marked the start of the vowel as the first downward zero-crossing following the start of periodic voicing.

Figure 9: Waveform and spectrogram showing segmentation of a stop-vowel sequence



Appendix 34: Final sentence list

The read sentences (Yorkston and Beutelman, 1981) were:

- 1) A full moon rose between two Eastern peaks
- 2) Look for pockets of black sand
- 3) We hope they will soon co-operate
- 4) Old telephone booths aren't easy to find
- 5) If he compromises he is accused of being too weak
- 6) He dashed across the car park and disappeared inside
- 7) The islands are sparsely populated
- 8) Contrast is important in life
- 9) At the sight of her owner she bounds about her pen joyfully
- 10) His trapping technique has worked well on hundreds in the past
- 11) Naturally these nations varied in terms of size population and resources
- 12) There are combinations of words that don't make sense
- 13) English has a rule that says two negatives make a positive
- 14) I hadn't even read for the part
- 15) Most weeds can now be put on the compost pile
- 16) From politics the emphasis shifted to economic affairs

© Excerpt of 16 sentences, which constitute less than 1% of the total number of word and sentence items in AssIDS, included under fair use provisions of UK Copyright Law.

The mood sentences (sentences one through three (Miller et al, 2008a) were:

- 1) The cake is too yellow
- 2) You dropped the sausages in the trifle
- 3) Sam is not a dog
- 4) He went to the park

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Appendix 35: Assessor recruitment poster

This requires a full page to itself, so is on the next page.



Volunteers Needed

To listen to recordings of people with Parkinson's disease

Prize draw:- You will be offered the opportunity to enter a prize draw for one £25 and five £5 Marks and Spencer vouchers

People with Parkinson's disease can have speech difficulties. This project aims to find out which factors affect their speech in the hope of better informing speech therapy.

The study is being led by Max Barnish with a multidisciplinary team from NSC and AHP. This team has conducted previous research on therapies for Parkinson's disease which has informed the NICE Guidelines for Parkinson's disease.

We need volunteers to help in assessing the intelligibility of some samples of speech from people with Parkinson's disease and their conversation partners.

We also asked participants to say some phrases in a happy, sad or neutral way and we need you to judge which "mood" was intended in the phrases you hear.

Who do we need?

- ❖ any UEA staff or students, except Year 3 SLT students
- ❖ people inexperienced in the speech of those with Parkinson's disease

What do we want you to do?

- ❖ listen to and watch some audio/video samples of the speech of people with Parkinson's disease and their conversation partners
- ❖ assess their intelligibility and mood being conveyed
- ❖ For a maximum of 1 hour

Where will this happen?

- ❖ Communications Laboratory, Queen's Building, UEA

To find out more contact

Max Barnish m.barnish@uea.ac.uk

Dr Katherine Deane k.deane@uea.ac.uk

or 01603 597047

12.13 Poster for recruitment of assessors

Appendix 36: Assessor recruitment press release

This is the pre-publication version, prior to minor amendments and typesetting by the Press Office. The final version was included in the staff and student bulletins.

Volunteers wanted for Parkinson's speech study

Researchers at UEA need people to volunteer to listen to samples of speech from people with Parkinson's disease and their carers for an hour.

The research team is trying to identify what makes the speech of someone with Parkinson's disease so hard to understand at times. This may help inform speech therapists in what to target when working with patients with Parkinson's.

The study is being led by Max Barnish as part of a multidisciplinary team from Nursing Sciences and Allied Health Professionals schools at UEA.

"This research study gives students an opportunity to listen to people with speech problems and really try to understand what is being said. This is particularly important for students studying to become healthcare professionals." said Dr Katherine Deane, Max's PhD supervisor.

We need people from UEA, staff and students, who are not expert at listening to people with speech impairments (So 3rd year SLT students and expert staff cannot take part).

The study will take 1 hour in Queens Building in the Communication Lab.

You will be offered the opportunity to enter a prize draw for one £25 and five £5 Marks and Spencer vouchers

For further information or to take part, please contact Max Barnish on m.barnish@uea.ac.uk

Appendix 37: Assessor information leaflet



Factors affecting the speech of people with Parkinson's disease

Assessor information sheet

We would like to invite you to assist the research team for the study "Factors affecting the speech of people with Parkinson's disease". The aim of our study is to investigate the relationships between cognitive impairment, speech impairment and impairment of everyday communication in Parkinson's disease. As one part of this investigation, we are assessing factors that affect how easy it is to understand the speech of people with Parkinson's disease and identify whether the speaker intended to sound happy, sad or neutral. The study is for Maxwell Barnish's PhD.

Who can take part?

UEA students and staff members who are fluent in English, have normal hearing and are not experts in listening to disordered speech are able to take part. Speech and language therapy students except for final year students can take part. In addition, people who have a close relative with Parkinson's disease or who currently work in groups for people with Parkinson's disease are not eligible to take part.

What would it involve for me?

If you decide to assist the research team in this way, it would involve coming to the Communication Laboratory in the School of Allied Health Professions, Queen's Building (building H1 on the UEA campus map). You would listen to speech from both people with Parkinson's disease and their conversation partners. In some parts of the study, you would be asked to write or type what words you hear. In other parts of the study, you would be asked to tick a box to say whether you thought the speaker intended to sound happy, sad or neutral. This involvement will last a maximum of an hour.

Are there any benefits for me?

You would be entered into a prize draw. The prizes will be one £25 and five £5 Marks and Spencer vouchers. You would also have the opportunity to contribute to research. Especially, for Faculty of Health students, this would provide an opportunity to become more familiar with the disordered speech of people who may be a major client group in your chosen profession. However, this study is not an assessed part of any course if you are a student at UEA.

Are there any risks for me?

We do not expect any risks in helping the research team in this way.

What if there is a problem?

If you become uncomfortable or distressed in any way whilst watching the videos or listening to the audio recordings, you can withdraw from being an assessor without giving a reason.

Confidentiality of people with Parkinson's disease

It is essential that you respect the confidentiality of the people with Parkinson's disease and their carers who have supplied the recordings. It is very important that if you recognize any of the speakers, you do not disclose this fact or the fact that they have Parkinson's disease to anyone. We will ask you to sign a confidentiality agreement.

Confidentiality of assessors

Your participation as an assessor will be kept confidential. No one outside the University of East Anglia will be told about your participation in any circumstances. Your name and school of study will be stored in a locked filing cabinet in a locked room at the university. Your name will not be used in the analysis or presentation of results. You will be asked to provide your UEA email address if you wish to enter the prize draw. This information will be stored securely and destroyed after the draw has taken place. The only situation in which the University of East Anglia would find out about your participation in the research is if there is a need to take disciplinary proceedings against you on grounds of misbehaviour in the course of the research. All personal data about you will be destroyed at the end of the study.

Who has reviewed the study?

The study has been approved for funding by the Health and Social Sciences Research Institute, University of East Anglia. All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee to protect your safety, rights, wellbeing and dignity. The study has been reviewed and given a favourable opinion by NRES Committee East of England.

Contacts

If you would like to assist the research team by listening to these recordings or would like further information, please email the Principal Investigator Mr Maxwell Barnish at m.barnish@uea.ac.uk or come and see him in room 0.27 Queen's Building.

Appendix 38: Assessor confidentiality agreement



Factors affecting the speech of people with Parkinson's disease

Assessor confidentiality agreement

(Assessor information sheet version 2 dated 01/29/2011)

Please
initial
box

- 1 As a collaborator to this research team, I will respect the confidentiality of all speakers I hear as part of this study
- 2 If I recognize any of the speakers, I will not disclose this fact or the fact that they have Parkinson's disease to anyone
- 3 I understand that should I breach this agreement, the University of East Anglia may take disciplinary proceedings against me
- 4 I understand that no one outside the University of East Anglia will be informed about my participation
- 5 I understand that the University of East Anglia will not be informed about my participation except in case of misconduct
- 6 I understand that I can withdraw from being an assessor at any time without giving a reason
- 7 I agree to act as an assessor for this research study

☐
☐
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Name of assessor:-

Signature:-

Date:-

Name of Investigator:-

Signature:-

Date:-

Appendix 39: Assessor answer book

Assessor ID:



'Factors affecting the speech of people with Parkinson's disease' study: Assessor answer book

Please sign the confidentiality agreement and leave it on your desk.

If you would like to enter the prize draw please complete the prize draw entry form and leave it on your desk.

Please complete the following background questions before starting

- 1) What is your age? _____
- 2) What is your gender? _____
- 3) What is your School? _____
- 4) If your School is AHP, is your course SLT, OT or PT? _____

Now you are ready to start the listening tasks.

There are 2 tasks

Everyone in the room will not be listening to the same file, so Max will ensure you know which file is yours.

Task 1:-

Please listen to the sentences and write down what you hear.

There is no need to take time to consider your answers

Mark how confident you were of your decision from 1 (the least confident) to 5 (the most confident)

If you have any questions about how to do the task, please ask Max.

This task has 42 questions

1) _____

Confidence (1-5):

2) _____

Confidence (1-5):

3) _____

Confidence (1-5):

4) _____

Confidence (1-5):

5) _____

Confidence (1-5):

6) _____

Confidence (1-5):

7) _____

Confidence (1-5):

8) _____

Confidence (1-5):

9) _____

Confidence (1-5):

10) _____

Confidence (1-5):

11) _____

Confidence (1-5):

12) _____

Confidence (1-5):

13) _____

Confidence (1-5):

14) _____

Confidence (1-5):

15) _____

Confidence (1-5):

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Confidence (1-5):

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Confidence (1-5): _____

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Confidence (1-5): _____

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Confidence (1-5): _____

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Confidence (1-5):

35) _____

Confidence (1-5):

36) _____

Confidence (1-5):

37) _____

Confidence (1-5):

38) _____

Confidence (1-5):

39) _____

Confidence (1-5):

40) _____

Confidence (1-5):

41) _____

Confidence (1-5):

42) _____

Confidence (1-5):

Task 2:

Please listen to the sentences and circle whether each sentence sounded happy, neutral or sad
There is no need to take time to consider your answers
Mark how confident you were of your decision from 1 (the least confident) to
5 (the most confident).

If you have any questions about how to do the task, please ask Max.
This task has 48 questions

1) Happy Neutral Sad
Confidence (1-5):

2) Happy Neutral Sad
Confidence (1-5):

3) Happy Neutral Sad
Confidence (1-5):

4) Happy Neutral Sad
Confidence (1-5):

5) Happy Neutral Sad
Confidence (1-5):

6) Happy Neutral Sad
Confidence (1-5):

7) Happy Neutral Sad
Confidence (1-5):

8) Happy Neutral Sad
Confidence (1-5):

9) Happy Neutral Sad
Confidence (1-5):

10) Happy Neutral Sad
Confidence (1-5):

11) Happy Neutral Sad
Confidence (1-5):

12) Happy Neutral Sad
Confidence (1-5):

13) Happy Neutral Sad
Confidence (1-5):

14) Happy Neutral Sad
Confidence (1-5):

15) Happy Neutral Sad
Confidence (1-5):

16) Happy Neutral Sad
Confidence (1-5):

17) Happy Neutral Sad
Confidence (1-5):

18) Happy Neutral Sad
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44) Happy Neutral Sad
Confidence (1-5):

45) Happy Neutral Sad
Confidence (1-5):

46) Happy Neutral Sad
Confidence (1-5):

47) Happy Neutral Sad
Confidence (1-5):

48) Happy Neutral Sad
Confidence (1-5):

This is the end of the study.
Many thanks for taking part.

Glossary

Term	Explanation
Cohort study	A research design that involves following a group of participants over time
Communicative participation	The use of communication to perform everyday tasks
Cross-sectional study	A research design that involves assessing participants at a single time point
Emotional conveyance	How successfully speaker mood and attitude are communicated to the listener
Formant	A prominent frequency band in a speech spectrum, resulting from the way in which the resonant properties of the vocal tract configuration for the sound shape the sound spectrum
Fricative	A consonant produced with turbulence, due to a narrow constriction in the oral cavity, for example /s/.
Fundamental frequency	The number of vocal fold cycles per second. Perceived as pitch.
General practitioner	A primary care physician in the United Kingdom
Harmonic-to-noise ratio	A measure of the relative strength of the harmonics in the speech sound- an indication of voice quality
Intelligibility	How successfully linguistic meaning is communicated from the speaker to the listener
Jitter	A measure of cycle-to-cycle variation in fundamental frequency- an indication of voice quality
Mixed factorial design	A research design that uses both between- and within-participants variables
Multimethod research	The use of multiple research methods in one study
Phoneme	A putative abstract unit of sound, expressed with regard to contrasts in a particular language. For example /b/ and /p/ are 'phonemes' of English

Phonetics	The study of speech production and perception. Some definitions include the use of sounds in particular languages.
Photoglottography	A semi-invasive means of examining vocal fold function, involving directing a light source onto the glottis (the vocal folds and the space in between)
Positivism	The belief that valid knowledge can only come from scientific and mathematical enquiry
Postpositivism	A philosophical approach that believes in absolute reality but recognises that it can only be accessed imperfectly
Pragmatics	The study of meaning in context
Prosody	The melody and rhythm of speech
Shimmer	A measure of cycle-to-cycle variation in amplitude- an indication of voice quality
Social constructionism	A sociological theory of knowledge that sees individuals and groups as contributors in the construction of their perceived reality
Spectrogram	A visual representation of sound frequency structure over time (in the time domain)
Spectrum	A visual representation of sound frequency structure at a given point of time (in the frequency domain)
Speed quotient	A measure of the symmetry of vocal fold function
Stop	A consonant produced by the release of an obstruction in the oral cavity, for example /t/
Striation	A vertical line on a spectrogram corresponding to a pulse of the vocal folds
Triangulation	The use of multiple methods of inquiry to examine a phenomenon, enabling cross-validation
Voice onset time	The time between the release of the oral constriction for stop production and the start of vocal-fold vibration
Waveform	A visual representation of sound amplitude over time
Within-participants design	A research design, in which different exposures are presented to the same group of participants,

rather than comparing between groups

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